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# Effects of Stigma on the Use of Spirituality by Older Black Men Living with HIV

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# Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral study by

Warren Miller

has been found to be complete and satisfactory in all respects,  
and that any and all revisions required by  
the review committee have been made.

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Walden University  
2018

Abstract

Effects of Stigma on the Use of Spirituality by Older Black

Men Living with HIV

by

Warren L. Miller

MSW, Howard University, 2009

BSW, Lamar University, 2008

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Social Work

Walden University

May 2018

## Abstract

Previous research on HIV stigma and the use of spirituality by people living with HIV/AIDS is scarce. Moreover, the research with older Black men who have sex with men (BMSM) is scant. The focus of this qualitative transcendental phenomenological study was to examine the lived experiences of BMSM living with HIV aged 50 and older with encounters of HIV stigma on the use of spirituality. The research questions were designed to explore the lived experiences of aging, HIV stigma, and spirituality. Conceptually, this study was framed within the minority stress theory and the HIV stigma framework. Data were collected through in-depth individual interviews, which provided detailed descriptions of the participants' experiences and created a basis for analysis. Ten participants from an HIV service organization in the Mid-Atlantic United States were selected for participation. Semi-structured interviews were digitally recorded, and data were coded and thematized using a modified van Kaam data analysis method, which led to the disclosure of 8 critical themes that illuminated the participants' lived experiences of living with HIV, aging, stigma, and spirituality. Older BMSM identified stigma as a stressor that reinforced the use of their spirituality. The results of this study may provide social workers, community organizations, and policymakers with data that inform a deeper understanding of the challenges older BMSM face due to HIV stigma. This study contributes to positive social change by providing practical information for social workers to inform intervention strategies that might reduce stigma and increase coping resources.

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## Dedication

I dedicate this study to all of those who have been and still are gatekeepers to the knowledge of the matter of HIV, young and older. Your courage, perseverance, and brazenness are encouraging. Most importantly, I dedicate this to the 10 participants who decided to share their stories and lived experiences with me on such a personal topic. Lastly, I dedicate this to my *Nanny*, Gloria, whose love and regard allowed me to stay the course during tough times.

## Acknowledgments

*“Sometimes you don’t realize your own strength until you come face to face with your greatest weakness.”* —Susan Gale

Firstly, I would like to thank my God, for which none of this would be possible. Deciding to embark on a doctoral journey is no small feat. One becomes increasingly self-aware and faces many areas of growth. So, I pat myself on the back for the courage to take this journey. I would like to acknowledge my family and friends who have been essential to this process from support, praise, encouragement, talks, and love. To my tribe, thank you for putting up with the unique challenges that come with having a family member/friend in a doctoral program.

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## Chapter 1: Introduction to the Study

### **Introduction**

Advances in HIV treatment has rapidly evolved over the past 30 years from treatment that was harmful to those being treated to establishing HIV as a manageable chronic disease. The beginning era of HIV devastated generations of gay men, denoting the disease with a universal stigma that has not been assuaged (Peltzer, Domian, & Teel, 2015). The second and third decades of HIV showed the world how racial and class disparities, along with better treatment, could shape communities to establish national strategies to combat HIV and how the disease could form into a manageable chronic disease (U.S. Department of Health & Human Services, 2016). Although there has been an increased understanding of knowledge around HIV, the future challenge of the decade to come involves developing an in-depth knowledge of aging with HIV (50 years of age and older) with people of color, specifically older Black men who have sex with men (BMSM). Black Americans make up 13.4% of the population in the United States but account for 45% of the HIV diagnoses in the United States (Centers for Disease Control and Prevention [CDC], 2016). The number is expected to rise for older BMSM living with HIV by 2020 (CDC, 2016). Despite advances in medical treatment, living with HIV as a chronic disease presents multiple challenges and can have significant psychological, social, spiritual, and physiological effects (Peltzer et al., 2015).

One psychological and social challenge that may come up for older BMSM living with HIV is stigma and how it impacts disease management and successfully aging (Porter, Brennan-Ing, Burr, Dugan, & Karpiak, 2015). Research on HIV stigma is

abundant (Earnshaw & Chaudoir, 2009; Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013; Herek, 1999; Herek, Gillis, & Cogan, 1999; Parker & Aggleton, 2003; Sengupta, Banks, Jonas, Miles, & Smith, 2011). However, there is little or no phenomenological information on the exploration the understanding of stigma on coping resources (e.g., spirituality) for older BMSM living with HIV. Therefore, it is imperative for researchers to explore the experiences of older BMSM living with HIV regarding the effects of HIV-related stigma on the use of spirituality. The information gleaned from this study can help service providers shape direct practice interventions with the population, inform policy development for services that target decreasing the stigma experience, and provide a basis for future researchers to address gaps found in the literature.

In Chapter 1, I include a summary of the existing literature about the background of the aging population, HIV with older BMSM, HIV in Washington, D.C., and spirituality. The problem statement is introduced and identifies the intersections of the research study. Additionally, there is an introduction to the conceptual and theoretical frameworks, research design and rationale, research questions, and nature of the study, all of which serve to rationalize the importance of the present study. I provide information on the assumptions, scope and delimitations, limitations, and significance of the study. I conclude with a summary of Chapter 1 and a preview of Chapter 2.

### **Background**

The U.S. population is aging as life expectancy continues to increase (Administration on Aging, 2016). In 2015, 18% of people in the United States were aged 60 and older, a 34% increase from 2005 (Administration on Aging, 2016). People 50



years and older are becoming more racially and ethnically diverse. Minority populations made up 22% (10.6 million) of older adults in 2015 with projections to increase to 28% by the year 2030 (Administration on Aging, 2016). Current researchers estimate that 1.5 million lesbian, gay, and bisexual (LGB) people are  $\geq 50$  years of age in the United States and that number will double by the year 2030 (Administration on Aging, 2016). Vance (2014) posited that by 2020, almost 70% of people living with HIV in the United States would be aged 50 and older (individuals who are 50 years of age and older). As the U.S. population increases in age, various challenges of healthcare and social issues may arise.

Older people in the United States may experience increasing complex health care and social service needs (National Institutes on Aging, 2015). Aging brings on challenges of disability, chronic illness, poverty, mental health, and issues with living situations (Yasamy, 2013). With an increase in the aging population, the need for social work and other helping professions in medical and nonmedical settings have increased (Rowe et al., 2016). One of the issues among older people in the United States is the HIV/AIDS epidemic (Mpondo, 2016). People over the age of 50 exhibits some of the same risk factors of younger people living with HIV, such as lack of knowledge of the disease, prevention, and having multiple sex partners (CDC, 2016).

HIV/AIDS is unique across various transmission categories, age groups, and race. In the United States alone, an estimated 1.2 million people currently live with HIV, with 12.8% undiagnosed and unaware of their HIV infection (CDC, 2015). Among the 1.2 million people living with HIV, people aged 50 and older make up almost 50% of the total HIV population (CDC, 2015). In 2014, 67% (191,083) of HIV infections were

attributed to the male-to-male sexual contact transmission category (CDC, 2015c).

Furthermore, BMSM accounted for an estimated 58% of all diagnoses among Blacks living with HIV (CDC, 2015b). Researchers have explored sociocultural constructs such as stigma, isolation, loss of family and friends, health/mental health issues, poverty, discrimination, issues with spirituality/religion, and fear as potential contributors to the higher prevalence of HIV/AIDS in the older BMSM communities (Blake, Taylor, & Sowell, 2017; Haile, Padilla, & Parker, 2011). Therefore, addressing any of the domains previously listed could potentially help decrease the transmission rate to older BMSM.

### **HIV and BMSM in the District of Columbia**

Just as HIV devastated the United States in the early 1980s, it continues to be a challenge for Blacks in the District of Columbia (D.C.), specifically older BMSM. As of 2014, D.C. had a population of 658,893, with Blacks making up 47.4% of the population (13.2% in the United States of America), 9.9% being of the Hispanic ethnicity within the Black race (U.S. Census Bureau, 2015). With Blacks making up almost half of the D.C. population, the prevalence of HIV is high in this community—75% of all cases of HIV (HIV, Hepatitis, STD, and TB Administration [HAHSTA], 2016). An estimated 9,617 men are living with HIV in D.C., with Black men accounting for 68% (6,524) of those cases. District residents who are Black, MSM, 50 years of age and older, have shown to have the highest rates of HIV at 5,272.8 cases per 100,000 persons in D.C. (HAHSTA, 2016). The advances in medication treatment, social, and psychological services in the D.C. area has helped people living with HIV live longer, but continued challenges exist with finding innovative ways to work with older BMSM living with HIV to address aging

successfully living with HIV (HAHSTA, 2016). Webel et al. (2014) suggested strengthening social support networks and reducing social isolations as ways of working with Blacks over the age of 50 living with HIV. In developing social support networks, Dalmida, Holstad, Dilorio, and Laderman (2012) posited that spirituality has proven to be a strategy with working with Blacks living with HIV and reducing experiences of social isolation such as stigma. The use of spirituality could be used to minimize experiences of stigma. However, there are no studies that appeared in my literature review that included the historical and social context of stigma and the use of spirituality in older BMSM living with HIV in Washington, D.C.

### **Spirituality, HIV, and Social Work**

Spirituality as a coping resource has been identified as a significant component in the lives of older people living with HIV (Porter et al., 2015). Spirituality and religion have served a major role in the Black community, and it provides a means of coping, improving the quality of life, managing risk factors for contracting HIV and managing psychosocial stressors (Dalmida et al., 2012). People living with HIV use spirituality to ensure a positive outcome in their lives. For example, Porter et al. (2015) found that older adults living with HIV use spirituality to assign meaning to stress reactions with successful aging with HIV. Lorenz et al. (2005) found that, of a sample of 2,266 people receiving care for HIV/AIDS, 85% ( $N = 1,926$ ) affirmed that spirituality was important in their lives. Seventy-two percent ( $N = 1,632$ ) relied on spirituality when making life decisions. Somlai and Heckman (2000) administered a 21-item spirituality and religion survey to 275 respondents. Forty-six percent of the respondents living with HIV engaged

in spiritual practices every day. Furthermore, Miller's (2005) study of 10 BMSM infected with AIDS suggests that engaging in spiritual worth practices can strengthen the lives of infected individuals. Spirituality has been noted as being a protective factor and use of resilience, specifically for African Americans (Himelhoch & Nije-Carr, 2016). However, due to the challenges of HIV-related stigma, older BMSM may not engage in spiritual practices or opportunities due to the negative experiences associated with stigma (Haile et al., 2011). As this population grows, it is important to understand the personal experiences of older BMSM living with HIV and how HIV stigma impacts their spirituality.

Social work is a profession that employs many different theories, approaches, interventions, and assessments to work with various populations. The use of spirituality in the human service populations, specifically social work, has been identified as the strength of the clients' ability to improve positive well-being (Dalmida et al., 2012; Hodge, 2011; Hugen, 1998). Hodge (2006) found that 60% of National Association of Social Worker (NASW) members, who are engaged in practice, use spirituality and religious means in their daily practices. Spirituality use in social work practice has gained popularity over the past two decades (Hodge, 2011). Social work practitioners often must incorporate the use of spirituality in practice to support the strengths and access unique populations, specifically older BMSM living with HIV.

Older BMSM living with HIV are at the intersection of race, sexual minority status, and age, which makes them vulnerable to not being participants of qualitative research that can provide an understanding of their lived experiences. Little is known

about older BMSMs' lived experiences with HIV-related stigma, particularly in the intersection of age and spirituality (Haile et al., 2011; Kum, 2017). In this study, I sought to address that gap.

### **Problem Statement**

HIV-related stigma has been a barrier to attaining positive well-being, HIV treatment, and care of people living with HIV/AIDS (Brown, Belue, & Airhihenbuwa, 2010). Due to the history of HIV being attributed as a “gay” disease, HIV stigma has infiltrated various communities but continues to be prevalent in BMSM communities (Haile et al., 2011). With increased life expectancy, older BMSM living with HIV will have to address challenges such as HIV-related stigma in their progression with the disease (Administration on Aging, 2015). Advances in medication treatment, social, and psychological services have helped people living with HIV live longer; however, continued challenges exist with finding innovative ways to serve older BMSM living with HIV (HAHSTA, 2016).

There is a need for the services of social workers, educators, and other professionals to assist with the needs of the aging population such as around areas of spirituality and religion (Blake et al., 2017; Brennan, 2008; Cahill & Valadez, 2013; Foster & Gaskins, 2009; Haile et al., 2011). Although researchers have suggested that spirituality has a positive outcome on well-being for people living with HIV, HIV-related stigma has not been well researched within this population; in addition, practices that inform successful aging with the disease have not been well studied (Brown, Hanson, Schmotzer & Webel, 2014; Buttram, 2015; Dalmida et al., 2012; Foster, Arnold,

Rebhook & Kegeles, 2011; Haile et al., 2011; Lorenz et al., 2005; Miller, 2005; and Tarakeshwar, Khan, & Sikkema, 2006). For example, Blake et al. (2017) posited a need for future studies on spirituality for older African American males living with HIV after administering focus groups and personal interviews with a convenience sample of 35 African American males living with HIV 50 years of age and older in the rural south to explore how they are aging with the HIV disease. Participants reported on six overlapping themes of stigma, self-care, family support, access to resources, coping with age-related diseases and HIV, and coping successfully. Molzahn et al. (2012) conducted narrative interviews of spirituality with 32 people living with serious illness, eight living with HIV. The researchers found that these stories revealed in-depth accounts of perspectives on life, illness, and existential crises. In the HIV accounts, there was an emphasis on the stigma having a negative impact on their lives. Despite these two examples, these studies are limited, as they lack the diversity in their samples related to HIV and race, and on HIV-related stigma and race (Molzahn et al., 2012). Few scholars have explored the experiences of HIV stigma among older BMSM living with HIV and the intersection of spirituality.

### **Purpose of the Study**

The purpose of this qualitative transcendental phenomenological study was to explore the lived experiences of older BMSM living with HIV in the context of understanding the effects of HIV-related stigma on their use of spirituality. No studies were available to date that account for the lived experiences regarding the intersection of HIV-related stigma and spirituality with older BMSM living with HIV. To address the

void in the literature, I used a qualitative methods design, establishing the study with a hermeneutics interpretivism approach. Sherman (1991) maintained that the interpretivism approach to qualitative research in social sciences continues to be an important approach due to the nature of capturing essential experiential scopes of the study's problem by incorporating participants as integral parts of the research process. Alternative to the positivist paradigm, the interpretivist paradigm includes assumptions that the reality of the participants is important to study to understand their social world in particular historical and social contexts (Ponterotto, 2005; Ritchie, Lewis, Nicholls, & Ormston, 2013). Individual semistructured interviews were used to explore the participants' lived experiences. The phenomenological methodological approach was used to identify common themes and patterns that will emerge from the interviews.

### **Research Questions**

The primary research question of this study was: What are the lived experiences of older BMSM living with HIV as it pertains to the effects of HIV-related stigma on the use of spirituality?

Additional subquestions included:

1. What are the lived experiences of older BMSM living with HIV?
2. How do older BMSM living with HIV describe their experiences of aging with HIV?
3. How do older BMSM living with HIV describe their experiences of HIV-related stigma?

4. How do older BMSM living with HIV describe the effects of HIV-related stigma on their use of spirituality?

### **Theoretical Foundation**

The theoretical basis that guided the study was Meyer's (2003) minority stress theory (MST). Expanded from social and psychological theoretical orientations and noted as the relationship between minority and dominant values, minority stress theory can help frame the role of stigma on coping resources in the lives of sexual minorities (Dentato, 2012). The minority stress theory proposes that health challenges are exacerbated among minority sexual populations such as MSM by stressors that perpetuate experiences of stigmatization, homophobic culture, internalized homophobia, and external prejudices (Dentato, Halkitis, & Orwat, 2013; Meyer, 2003). Meyer posited that the prejudice and stigma experienced by the lesbian, gay, bisexual, and transgender individuals cause stressful reactions on global functioning. The minority stress theory may partially connect the experiences of HIV-related stigma on the spirituality of older BMSM living with HIV. The minority stress theory stresses the importance of understanding the cultural and social context of stressors experienced by sexual minority populations. The current study included the minority stress theory to understand the social and cultural context of stigma on the use of spirituality of older BMSM living with HIV through the themes of the research questions.

### **Conceptual Framework**

HIV is a treatable and manageable chronic disease. The challenges of these myths and fears contribute to the perpetuation of HIV-related stigma. HIV-related stigma



intensifies other stigmas associated with older adults living with HIV, such as ageism, sexism, and racism (Karpiak, Shippy, & Cantor, 2006). Therefore, it is essential to understand how stigma is defined, experienced, and explored with people living with HIV.

The conceptual framework that guided this study was an integrated model of Herek's (1999) and Earnshaw and Chaudoir's (2009) HIV-related stigma frameworks to explore the micro level interaction of HIV-related stigma. Herek described an HIV/AIDS-related stigma framework with an emphasis on the cultural and individual contexts of stigma. Parker and Aggleton (2003) expanded Herek's conceptualization of the HIV/AIDS-related stigma framework by purporting that the psychological and behavioral models of addressing HIV/AIDS-related stigma are not sufficient, with a need for including social processes in examining HIV/AIDS-related stigma. Herek et al.'s (1998) conceptualization of cultural and individual levels of HIV/AIDS-related stigma suggests that people living with HIV/AIDS experience cultural and individual challenges with stigma. Similarly, Earnshaw and Chaudoir posited that HIV-related stigma is a multilayered process people living with HIV experience through stigma mechanisms of internalized, anticipated, and enacted forms stigma. However, the researchers did not examine stigma at the personal and cultural level. Older BMSM living with HIV/AIDS experience multiple stigmas (Haile et al., 2011). This conceptual framework is appropriate for phenomenological study in that the interview questions enabled participants to describe and narrate their lived experiences within a personal and cultural context of HIV/AIDS-related stigma on their use of spirituality. Subsequent research,

expansion, and application of this framework offered a context to explore HIV-related stigma, allowing for exploration into the experiences stigma on use of spirituality of older BMSM living with HIV (Earnshaw et al., 2013; Parker & Aggleton, 2003; Sengupta, Banks, Jonas, Miles, & Smith, 2011). The interview guide was developed to gather individualized and cultural responses that are designed to develop a holistic understanding. The conceptual framework is expanded in Chapter 2.

### **Nature of the Study**

I used a qualitative phenomenological approach in this study to explore the lived experiences of older BMSM living with HIV. This approach allowed for the examination of the in-depth experiences of respondents who experienced a specific phenomenon (Creswell, 2009). The goal of qualitative methods is to uncover and discover patterns that help explain a phenomenon of interest. This study set out to explore the lived experiences of older BMSM living with HIV in the context of understanding the effects of HIV-related stigma on the use of spirituality. A qualitative research method and a phenomenology paradigm allowed for the exploration of lived experiences in detail.

In this approach, I attempted to understand how older BMSM living with HIV describe and ascribe meaning to their first-hand experiences. Transcendental phenomenology (TP) is a philosophy that aligns with the qualitative methodology and with the goal of understanding the human experience (Sousa, 2014). TP is based on the premise of controlling all preconceived notions of viewing the phenomena through a clear lens, allowing the organic development of phenomena to emerge from the study's process (Husserl, 1977; Sheehan, 2014). TP is associated with focusing on the subjective

experiences and interpretations of the world of the participants in the context of phenomena (Creswell, 2009). To that end, I conducted individual interviews with the participants to hear the essence of their lived experiences. I used a purposive sampling strategy (Patton, 2015) to recruit participants who met unique criteria. The participants were BMSM aged 50 and older living with HIV in the metro D.C. area. The participants had to have been receiving HIV treatment for the past year, spoke and understood English, had had experiences with HIV stigma and spirituality, and be without adverse cognitive challenges to adequately consent to participate in the study.

### **Definitions of Terms**

The following are the operational definitions of the terms used in this study:

*Acquired Immunodeficiency Syndrome (AIDS):* AIDS is the final stage in the stages of HIV that results in damage to the immune system, increasing numbers of opportunistic infections (CDC, 2017).

*Black or African American:* A person having origins in any Black racial groups of Africa (U.S. Census Bureau, 2017). The terms were used interchangeably.

*Epoche:* The process of suspending preconceived judgments, opinions, feelings of a phenomenon to emphasize the analysis of the experience (Moustakas, 1994).

*Horizontalization:* The process of phenomenological reduction that equalizes all of the raw data collected from participants (Moustakas, 1994).

*Human Immunodeficiency Virus (HIV):* A virus that attacks the immune system, specifically CD4 cells, which helps to fight off infection (CDC, 2017).

*HIV/AIDS-related stigma:* A concept that refers to the discrimination, prejudice, negative attitudes, and abuse directed at people living with HIV and AIDS (Stutterheim et al., 2009).

*Lived experiences:* Given (2008) stated, “experiences as we live through it and recognize it as a particular type of experience” (p. 616). A first-hand account of phenomena.

*Older:* For this study, older refers to individuals 50 years of age and older.

*Men who have sex with men (MSM):* The World Health Organization (2015) describes MSM as men, including those who do not identify as same gender loving or bisexual, who engage in sexual activity with other men.

*Phenomenological reduction:* Also known as *bracketing*, which is the act of checking personal judgment of the phenomena as it relates to the natural world (Moustakas, 1994).

*Sexual minorities:* A group that is comprised of individuals who identify with sexual orientation, practice, and identity that is different from the majority society (e.g., Lesbian, Gay, Bisexual, Transgender, Questioning, Intersex) (Math & Seshadri, 2013).

*Spirituality:* Although this study does not have a formal definition of spirituality, Koenig, McCullough, and Larson (2001) offered a definition that includes the summation of literature defining spirituality:

Spirituality is the personal quest for understanding answers to ultimate questions about life, about meaning, and about the relationship to the sacred or

transcendent, which may (or may not) lead to or arise from the development of religious rituals and the formulation of community. (p. 18)

*Transcendental phenomenology*: A scientific inquiry that sets out to study experiences from a first-person point of view in an unbiased and free of all preconceived ideas manner (Husserl, 1963).

### **Assumptions, Scope and Delimitations, and Limitations**

#### **Assumptions**

This study involved the exploration of the lived experiences of HIV-related stigma on spirituality use in older BMSM living with HIV who receive HIV/AIDS services through various AIDS service organizations. The first assumption was that older BMSM living with HIV have experienced HIV-related stigma and participated in the use of spirituality at a point in their lives. Another assumption was that there would have been accessing to these individuals who have experienced the phenomena of interest. Additionally, the respondents would agree to be a central part of the study, engage, and provide truthful answers to the interview questions. Methodologically, there was an assumption that bracketing would allow the participants' perspectives to lead (Leedy & Ormrod, 2010). Lastly, the purpose of the study was to explore the lived experiences of older BMSM living with HIV with experiences of HIV-related stigma and the use of spirituality in Washington, D.C. It was assumed that the participants provided rich-detailed experiences of the phenomena.

**Scope and Delimitations**

The selection of the location was limited to a metropolitan area of Washington, D.C. that includes the major areas of Maryland and Virginia focusing on older BMSM ( $\geq 50$  years of age), living with HIV/AIDS, and who receive current services from local AIDS service organizations that have a psychotherapy, case management, and/or treatment adherence component. Individuals who identified as female, non-African descent, not living with HIV,  $\leq 50$  years of age, and live outside of the geographical location were not eligible to participate in this study. There was no age capitation for this study. Participants could not have adverse medical issues that impeded or adversely impacted the ability to participate such as dementia, cognitive processing issues, and severe psychiatric symptoms. The purpose of the study was to explore the lived experiences of older BMSM living with HIV. Transferability is limited due to the nature of the study. However, I have provided a detailed description of the data collection and data analysis in Chapter 3. The scope and delimitations of this study limit the current findings to the participants of this study.

**Limitations**

The design required the voluntary participation of older BMSM living with HIV in the study. Because of the confined inclusion criteria, there was potential for difficulty in recruiting participants. To produce a more significant outcome in recruitment, I used a snowballing technique to recruit participants once the first participants were recruited. Other limitations of this study included generalizability, social desirability, and potential researcher bias. First, the study is limited regarding its generalizability to the entire

population of older BMSM living with HIV. Like any other minority sexual group, the older BMSM population is heterogeneous. An issue of including specific members of this population exists. I attempted to retrieve a sample of the population through purposeful qualitative sampling procedures. Second, this study solicited self-reported sensitive information on a subject that is sensitive and difficult to explore (Blake et al., 2017). Social desirability may have been a limitation. At the beginning of the research interview, I suggested that participants be completely open and honest during the process. I used journals and field notes to monitor judgment of personal experiences and perceptions to manage researcher bias. This manageability process is further discussed in the role of the researcher in Chapter 3.

### **Significance of the Study**

The lack of literature on this topic charges researchers to explore the lived experiences of older BMSM living with HIV (Emlet, 2007; Haile et al., 2011). Older BMSM living with HIV are a particularly vulnerable group because of their increased risk of coping challenges with successful aging with this disease (Abbott & Williams, 2015; Blake et al., 2017; Emlet, Harris, Pierpaoli, & Furlotte, 2017). HIV among the older BMSM population is at an endemic stage. Moreover, there are no studies, to date, which explore HIV stigma's impact on this population's ability to cope with living with HIV. Little research has been conducted on older BMSM living with HIV in the United States and this geographical location. Addressing the needs of this population by examining their lived experiences on HIV stigma on the use of spirituality is crucial to

the National HIV/AIDS strategy of increasing treatment and understanding of innovations in working with higher risk populations.

### **Significance to the Social Work Profession and Practice**

There is a plethora of literature in social work and spirituality, but not much literature concerning social work, spirituality, and HIV stigma. The social work profession has been involved in the field of HIV/AIDS (Emlet et al., 2017; Emlet, 2007); however, the literature is scarce regarding older people, specifically, older BMSM living with HIV. Advanced age, along with an HIV diagnosis, increases the risk of experiencing stigma. Experiences of stigma may potentially impact functioning (Haile et al., 2011). Therefore, it is important that social workers have the most current knowledge of what this population understands as their experiences of HIV stigma on their use of spirituality. The information gleaned from this study could help service providers shape direct practice interventions with the population, inform policy development for services that target decreasing the stigma experience, and a basis for future researchers to address gaps found. By understanding the experiences of older BMSM living with HIV regarding HIV-related stigma on the use of spirituality, there is potential to tailor interventions and practice methods used by social work providers. Furthermore, as minority stress theory gains importance in sexual minority research, this study helps build the evidence for its use in research studies. To conclude, the findings from this study can have an impact on shaping policies that target program development for addressing HIV-related stigma in communities of color.



### **Implications for Social Change**

A multitude of evidence suggests that spirituality has positive outcomes for people with a terminal illness (Brown et al., 2014; Buttram, 2015; Dalmida et al., 2012; Foster et al., 2011; Lorenz et al., 2005; Miller, 2005; Tarakeshwar et al., 2006). People living with HIV/AIDS require improved care and a voice in the research process. It is important to include unique populations that historically have had little to no voice in research as it pertains to identifying and attempting to understand the experiences of HIV-related stigma on the use of spirituality in older BMSM living with HIV.

The narratives that emerged from this study can inform the development of specific spiritual-led social work interventions that may potentially have a positive impact on the lives of this population. The findings create a more informed, in-depth view and understanding of HIV-related stigma on the use of spirituality for older BMSM living with HIV. The results of this can impact how spirituality is defined and incorporated into local provider practices for addressing psychosocial challenges. Older BMSM living with HIV are disproportionately affected by this epidemic overall, and the level of services provided for treatment of psychosocial issues should be equitable and diverse. Having a nuanced understanding of how stigma influences use of spirituality by older BMSM living with HIV can help social change agents create innovative treatment interventions.

Also, to the individual level of social change, implications for community and societal change exists. Although the HIV/AIDS challenge is not new to this metropolitan area, communities often neglect this topic of interests until it becomes necessary to

respond. An opportunity exists for communities to become better informed about the lived experiences and needs of older BMSM living with HIV/AIDS. Communities can use the results from this study to help identify areas to focus specialized social service efforts and agendas that directly impact the population.

### **Summary**

HIV stigma and spirituality are constructs that warrant a research focus in the lives of sexual minority populations, specifically older BMSM living with HIV. The aging population continues to be the subject of health, social, gerontology, and aging research inquiry due to the increase of HIV/AIDS in this population in the last decade (Administration on Aging, 2016). This study explored the lived experiences of older BMSM living with HIV with a focus on HIV stigma on the use of spirituality. This research aimed to provide older BMSM living with HIV an opportunity to express their lived experiences, and to provide an in-depth description of their experience with HIV stigma on the use of spirituality. A qualitative inquiry using a phenomenological approach was used to explore the experiences of HIV stigma on the use of spirituality.

In Chapter 2, I provide an expanded review of the literature in the discipline related to the topics studied and built the case further for the need for research and the choice of theoretical and conceptual frameworks.

## Chapter 2: Literature Review

### **Introduction**

Experiences of HIV-related stigma are noted in research among minority populations living with HIV such as within the African American community (Haile et al., 2011). Despite the importance, a lack of knowledge and research on how older BMSM is living with HIV experience HIV-related stigma on the use of spirituality continues to be a problem. Furthermore, with the consistent increase of HIV in the aging population, especially within the BMSM community, there are concerns about the innovative ways this population cope with HIV (Coleman, 2017).

The literature review includes the following: the theoretical and conceptual frameworks of minority stress theory and HIV/AIDS-related stigma, concepts of spirituality and HIV, and information on older BMSM. The literature review begins with an examination of the literature related to minority stress theory and HIV/AIDS-related stigma. Second, the literature regarding spirituality, spirituality and HIV, and spirituality, HIV, and older BMSM are examined. Limitations in the literature are identified throughout the review.

### **Literature Search Strategy**

#### **Databases, Search Engines, and Key Search Terms**

Research and theoretical literature were accessed from the Walden University Library system and Google Scholar. Academic databases used included Academic Search Complete/Primer, ProQuest Central, SocINDEX, PsycINFO, LGBT Life with Full Text, CINAHL & MEDLINE, SAGE Journals, Google Scholar, and SAGE Research Methods

Online. The following keywords were used to begin my primary search on HIV-related stigma on the use of spirituality of older BMSM living with HIV: *HIV/AIDS, HIV-related stigma, stigma, spirituality use, spirit\*, older adults and HIV, men who have sex with men, Black, BMSM, aging, HIV, and spirituality, qualitative studies on aging and HIV, stigma and HIV, gay, aging, and HIV, and minority and HIV*. Other themes required additional search criteria necessary to explore the conceptual framework. These search criteria included: *HIV/AIDS-related stigma conceptual frameworks, stigma frameworks, stigma and spirituality frameworks, phenomenology, and transcendental phenomenology*. Additional themes for MST required an additional search. These search criteria included *Minority Stress Theory, MST, Minority Stress Theory and HIV, MST and HIV stigma, MST and Spirituality, and MST BMSM*.

This search in the multiple databases yielded over 500 articles on diverse aspects of the subjects under study. The selection of the relevant literature material included peer-reviewed published articles from journals between 1998 and 2017, government agency documents on demographics, incidence, the prevalence of HIV and aging between 2014 and 2017, and original works on various conceptualizations of spirituality, stigma, and phenomenology between 1960 and 2013. Articles that were not focused on the identified constructs of this study were not included. This is not an exhaustive list of the literature of the constructs involved in this study.

## **Theoretical Foundation**

### **Minority Stress Theory**

MST provides a theoretical foundation for why MSM living with HIV may have poorer experiences of quality of life and health due to HIV/AIDS-related stigma (Meyer, 1995). MST is rooted in the foundation of sociological and psychological theories (Meyer, 1995, 2003). Elaborating on the social stress theory, Meyer developed MST to propose that the challenging effects of stress on mental health involve interrelated patterns of the events over time (Lazarus, 1966; Pearlin, 1983). Meyer (1995, 2003) proposed this theory that focused on chronic and acute stress experiences of sexual minorities (e.g., LGB). Meyer (2003) initially applied the minority stress perspective to understand the stress processes on mental health associated with sexual minority status. Meyer further applied the minority stress perspective to the psychological distress among gay men. Though Meyer focused mainly on the sexual minority community, minority stress has been used by other scholars to understand the minority stress experience among other minority statuses, such as race (Williams, 1986) and gender (Schwartz, 1991). Additionally, current researchers have used the MST or some variation of the theory to explore various outcomes of minority stress and psychological distress (Livingston, Christianson, & Cochran, 2016; Szymanski, Ikizler, & Dunn, 2016; Szymanski & Sung, 2010). Recent researchers have examined minority stress and psychological distress on lesbian and bisexual women with breast cancer (Kamen, Jadson, Mustian, & Boehmer, 2017), alcohol use (Hatzenbuehler, Corbin, & Fromme, 2011; Livingston et al., 2016), and HIV stigma (Hatzenbuehler, 2009; Herek, Gillis, & Cogan, 2009). However, in this

study, MST was applied to older BMSM living with HIV. MSM might not necessarily identify as a sexual minority, but they can (Millett et al., 2012). The assumptions of MST provided a theoretical foundation for this study and its population.

Assumptions of MST includes that minority stress is: a) exclusive (not experienced by nonstigmatized populations), which requires minority individuals to develop and use coping mechanisms to adapt to stress experiences that are beyond the regular stress experience; b) chronic, where the minority individual is subject to conflict due to challenges with social and cultural structures of the dominant group; and c) socially based, which describes minority stress from social process, institutions, and structures outside of the individual (Dentato, Halkitis, & Orwat, 2013; Meyer, 2003).

Minority stress is described as stress process experienced by individuals from stigmatized groups due to their minority status (Meyer, 2003). Researchers suggest that MST emphasizes the stress process (experiences of prejudice, rejection expectations, internalized homophobia) and the coping process (Meyer, 2003; Pearlin, 1999). Minority stress is based on the difference between societal and minority values in which the cultural standards of the minority person do not align with the majority group (Dentato et al., 2013). As a result, minority group members who identify with sexual minority statuses and those who do not, but share similar minority statuses (person of color, living with HIV), may be exposed to negative life events such as prejudice, stigma, and discrimination. MST provides a foundation for understanding the process of social situations that are specific to the minority position that may impact mental health (Meyer,

2003). MST can also extend to describe certain types of stressors such as HIV/AIDS-related stigma.

HIV/AIDS-related stigma is a stressor associated with minority stress brought on by society's negative regard toward a minority group (Herek, 2007). Meyer (2013) explained the MST process in a distal and proximal continuum, where distal stressors are described as events that happen outside of the affected minority, and proximal stressors are described as the internalization of social attitudes. An example of distal stressor is enacted stigma, which produces experiences of discrimination or microaggressions. On the other hand, an example of a proximal stressor is internalized stigma, which produces internalized homophobia experiences. In turn, the MST proposes that these stressors might lead to adverse health outcomes related to mental and physical health (Meyer, 2013). Much of the literature on the MST and HIV/AIDS-related stigma is associated with sexual minority identity (Feinstein, Goldfried, & Davila, 2012; Hatzenbuehler, 2009; Pachankis et al., 2015). However, there are no studies that appeared in the literature review with a focus on the experiences of the effects of HIV/AIDS-related stigma on spirituality use, which is associated with positive physical and mental health outcomes for gender and sexual minorities who experience minority stress exist to date (Dalmida, Holstad, Dilorio, & Laderman, 2009; Dalmida, Koenig, Holstad, & Wirani, 2013).

In his original research study, Meyer (1995) examined the minority stress model with a sample of gay men ( $N = 741$ ) in New York City and found that prejudices, perceived stigma, and internalized homophobia meaningfully projected psychological distresses such as demoralization, guilt, suicide, AIDS transmission status, and sex

problems among his sample. Meyer's research provides evidence that supports the minority stress theory as essential to the framework of understanding how perceptions of minority stress associated with sexual minority status influence negative psychological health.

As previously mentioned, much of the research is related to minority stress and sexual minority identity and focuses on white gay men. The application of MST is relevant to explore the experiences of older BMSM living with HIV, as it is related to stigma experiences on their spirituality. The exclusive experiences of older BMSM living with HIV, who belong to at least three minority groups, needed to be explored.

### **Conceptual Framework**

#### **HIV/AIDS-Related Stigma**

According to proponents of MST, the most prominent factor for people living with HIV experiencing reduced quality of life is stigma and discrimination (Dentato et al., 2013; Meyer, 2003). In their study of stigma on psychological well-being in older adults living with HIV, Porter et al. (2017) found that older adults in the United States living with HIV experience some form of stigma in their lifetime. The types of stigma usually experienced includes personalizing stigma, negative self-image, disclosure concerns, and public attitudes (Porter et al., 2017). The conceptual framework that informed this study's interview guide, data analysis, and discussion of results was an integrated model of Herek's (1999) and Earnshaw and Chaudoir's (2009) HIV-related stigma frameworks to explore the micro level interaction of HIV-related stigma. Both models assume that people living with HIV experience some form of stigma in their



lifetime (e.g., anticipated, internalized, and enacted). Although both models are focused on the societal factors of stigma, individually there is a limitation to both models exploring individual and cultural levels of HIV-related stigma for people living with HIV. Therefore, integrating the models to explore the lived experiences, analyze data, and inform the discussion drove the study.

It is imperative to understand the complexities of HIV/AIDS-related stigma (referred to as HIV stigma going forward). Stigma is a broad and multifaceted concept. In Goffman's (1963) seminal study, he defined stigma as "An attribute that is deeply discrediting . . . A situation of an individual who is disqualified from full social acceptance" (pp. 2–5). More recently, HIV stigma has been defined as abuse, prejudice, and negative attitudes toward people living with HIV and AIDS (Alonzo & Reynolds, 1995; Emlet, 2007; Herek, Gillis, & Cogan, 1999; Poindexter & Linsk, 1999; Porter et al., 2017). Green and Platt (1997) and Herek (1999) posited four foundational characteristics that make HIV vulnerable to high stigmatization: (a) the disease is the individual's responsibility, (b) the illness and diseases are unalterable or degenerative, (c) the illness and diseases that are perceived to be contagious, and (d) when illness and disease is readily apparent than others. HIV stigma continues to situate people living with HIV in a stigmatized role because contraction of HIV is usually considered immoral; it is an incurable disease, there is a level of stigma attached because it is an illness, and there is a level of having symptoms associated with the disease in different advanced stages (Herek, 1999). Older BMSM also holds identities in other marginalized groups (e.g., men

who have sex with men, ethnic minority, people 50 and over), which creates another level of potential experience of stigma and discrimination.

HIV stigma can be interpreted and applied to interpersonal, intrapersonal, and societal levels of interaction (Earnshaw & Chaudoir, 2009; Emlet, 2009; Steward et al., 2008). Within these levels of interactions, people who live with HIV experience different types of HIV stigma. Earnshaw and Chaudoir (2009) proposed that people living with HIV can participate in internalized, anticipated, and enacted HIV stigma. Moreover, they proposed an HIV stigma framework in which on stigma is a social process for people living with HIV and HIV uninfected people, and how it can impact stigma mechanisms (e.g., prejudice, stereotypes, discrimination, enacted stigma, anticipated stigma, internalized stigma; Earnshaw & Chaudoir, 2009). People living with HIV, who might confront these stigma mechanisms, may experience internalized, anticipated, and enacted stigma. Internalized stigma is described as the negative beliefs and feelings about HIV that people living with HIV validate to themselves (Earnshaw & Chaudoir, 2009). The activation of enacted HIV stigma includes individuals living with HIV thinking about prejudice and discrimination from others due to them living with HIV. Anticipated stigma involves the perceptions of people living with HIV on expecting prejudice and discrimination in the future.

Researchers conceptualize HIV stigma as a stressor that impacts personal welfare and coping resources for people living with HIV/AIDS (Chaudoir et al., 2012). Scholars have found that the experience of HIV stigma can lead to poorer coping strategies, feelings of shame and guilt, mental, spiritual, and physical stress (Chaudoir et al., 2012;

Grodensky et al., 2015). The evidence is undecided on the experiences of HIV stigma, age, sexual minority status, race, and spirituality use. One study showed that older people of color living with HIV reported higher levels of an HIV stigma experience compared to younger adults (Emlet et al., 2015), but a different study showed the opposite to be true (Slater et al., 2013). There is a lack of literature available on the issue of HIV stigma among older adults (Berg & Ross, 2014; Emlet, 2006). Furthermore, there are fewer studies exploring stigma in older BMSM living with HIV (Foster & Gaskins, 2009; Haile et al., 2011). Consequently, the understanding of HIV stigma is limited regarding this population and even more restricted in the area of spirituality.

Haile et al. (2011) posited that the relationship between HIV stigma and HIV related disparities must be examined through close engagement with the lived experiences of older BMSM living with HIV. In their qualitative study examining the life history narratives of 10 gay and bisexual black men over 50 living with HIV/AIDS in New York City, Haile et al. found that older Black gay and bisexual men over 50 felt that stigma marked them as another component in the social and medical systems that perpetuate dehumanization, perceived levels of stigma informs social position in social situations, and that stigma has emotional and physical consequences on their well-being and global functioning. With there being limited knowledge about the stigma experiences of older BMSM living with HIV, the research suggests that HIV stigma may be an ongoing barrier to quality of life, well-being, aging successfully, and psychological issues (Emlet, 2006; Haile et al., 2011; Smit et al., 2012). For example, researchers suggest that HIV stigma negatively impacts the quality of life among people living with HIV (Slater

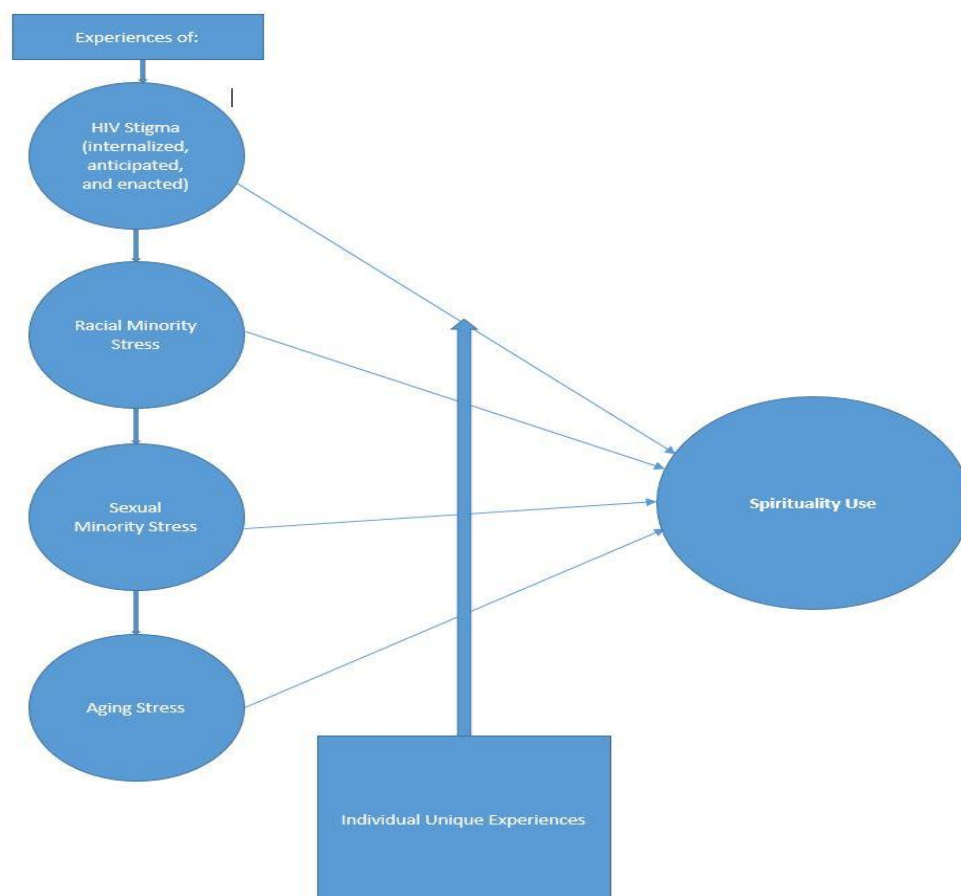
et al., 2015). Additional researchers argue that HIV stigma is a significant component of the deconstruction of social power and coping resources for aging people living with HIV (Porter et al., 2017; Rueda, Law & Rourke, 2014).

HIV stigma impacts how aging communities use spirituality as a coping resource for health-related stressors (Porter et al., 2017; Vance, Brennan, Enah, Smith, & Kaur, 2011). HIV can be described as a stressor for all populations, but more in aging populations (Fang et al., 2015). Older people who are challenged by HIV may have some experiences to HIV stigma, which may stress how they use various coping resources (e.g., spirituality use). With the significant amount of literature regarding spirituality and HIV, there is limited literature surrounding these constructs within the older population, and more limitations to the population of older BMSM living with HIV, HIV stigma, and use of spirituality. The use of an HIV stigma framework helped situate and explored the lived experiences of this population regarding their individualized (internalized and anticipated stigma) and cultural/social (enacted stigma) experiences of HIV stigma on the use of spirituality through the interview questions developed.

### **Application of Theoretical and Conceptual Frameworks to Study**

To explore the effects of HIV/AIDS related stigma on the use of spirituality, I used MST (Meyer, 2003) and an HIV/AIDS-related stigma framework (Earnshaw & Chaudoir, 2009; Herek, 1999). Within this integrated framework, the experiences of HIV/AIDS-related stigma and minority stressors (e.g., racial, aging, and sexual) on the use of spirituality was explored through individual lived experiences of older BMSM living with HIV. This modified version of the theoretical and conceptual frameworks

informed the process for data collection, interpretation of the data, and discussion sections of this study (See Figure 1).



*Figure 1.* MST and HIV/AIDS stigma model on spirituality use.

### **Conceptualization of Spirituality**

Before understanding the use of spirituality in older BMSM living with HIV population and relation to HIV stigma, it was imperative to define the concept. The concept of spirituality cannot be used to imply one standard meaning. The literature on spirituality is complete of various perspectives, concepts, definitions, and assumptions of the definition of spirituality (Borges, Santos, & Pinheiro, 2015; Emlet et al., 2017;

Starnino, 2016; Trevino et al., 2010). Skalla and MaCoy (2006) conclude that spirituality is part of a person's inner being within that helps create humanity. Spirituality is also described as "a quality of the inner self or soul – the deepest conscious of who we are, what is right and wrong and what gives us meaning and purpose" (Sheafor & Horejsi, 2005, p. 32). Spirituality can also signify a relationship between God and devotee (Barry & Connolly, 1982). Kliewer (2004) has defined spirituality as a search for what is holy and sacred in life. Although the researchers above have worked to define spirituality, other researchers purport that spirituality is not easy to define (Carroll, 2011; Corbin, 2007; Senreich, 2013). Therefore, contextualizing spirituality can be difficult.

In further examining the literature around the conceptualization of spirituality, there have been attempts to differentiate spirituality from religion. Commonalities exist between both constructs, but there are essential differences. Religion refers to the face of faith (Rowe & Allen, 2004). Sheafor and Horejsi (2005) assert that religion is a set of beliefs, values, traditions that take care and support approaches to spiritual growth. Religion provides a language for describing and understanding the spiritual life. Religion is identified as a doctrine and linked to an institution (Emlet et al., 2017). Conversely, spirituality is an individualized process that is unique to the cultural beliefs and practices of an individual with no formal connection to doctrine (Canda, 2013; Garg, 2017; Gomi, Starnino, & Canda, 2014; Pawar, 2016). Hill et al. (2000) posited that spirituality is not confined to religiosity. Someone can be spiritual and not "religious." Spirituality is often described as not having physical components but transcending the physical boundaries of time and space. Alternatively, Hill et al. theorized that religion involves three main

dimensions: individuals are committed to a supernatural power outside of themselves, the ritualistic acts carried out to admire that power and a positive feeling in the individual who believes in the power. Definitions of spirituality are challenging to construct due to the individualistic experiences that are impacted by life experiences, cultural and social influences, and gender (Hill & Pargament, 2003). In its simplest and broadest form, spirituality has been described as a personal connection to self, others, and a higher being that exist in the universe (Canda, 1983). Conceptualizing spirituality is important to understand the dimensions of the concept. Koenig, McCullough, and Larson (2001) conceptualized spirituality as:

Spirituality is the personal quest for understanding answers to ultimate questions about life, about meaning, and about relationship to the sacred or transcendent, which may (or may not) lead to or arise from the development of religious rituals and the formulation of community. (p. 18)

However, for this study, there was no specific identified definition due to the exploratory nature of the study. Nevertheless, a need existed for examining the literature of spirituality in the Black community, aging and HIV, and older BMSM living with HIV.

### **Spirituality, Stigma, and HIV**

Few researchers have examined spirituality, stigma, and HIV. Moreover, there are no studies that have the concepts of spirituality, stigma, and HIV regarding older BMSM. Chaudoir et al. (2012) explored the three concepts along with psychological well-being amongst a sample of 465 people living with HIV/AIDS. In a cross-sectional study, researchers found that spiritual peace buffered the effects of stigma on depression in their

sample, which accounts for spirituality as being important in counteracting the effects of HIV stigma. In a phenomenological study of 18 Black women living with HIV, researchers found that there was an importance in church and spiritual activity that mediated the negative effects of stigma by allowing them to be in a physical space of support (Sanicki & Mannell, 2015). Similarly, in a sample of Malaysian individuals living with HIV, researchers found that stigma experienced was rated higher than other studies, and that individuals with higher spiritual values reported reduced stigma experiences (Nadia, Leelavathi, Narul-Aida, & Diana, 2017). Spirituality is shown to have an impact on HIV stigma. However, there is limited research on the concepts. To the best of my knowledge, no studies exist that explores the effects of HIV stigma on the use of spirituality, especially of experiences of older BMSM.

### **Spirituality among the Black Community**

Spirituality is a common element in the lives of Blacks that promotes strength, hope, and purpose in life (Armstrong & Crowther, 2002; Bowen-Reid & Smalls, 2004; Hendricks, Bore, & Waller, 2012; Lewis, 2008; Mattis, 2000, 2002; Mattis & Jagers, 2001; Taylor & Chatters, 2010). Although historically, spirituality and religiousness has not always been a source of strength for many people living with HIV (Vance et al., 2011), spirituality for Black communities has been linked to situating a framework for how Blacks view and solve their personal, social, and community problems, and connect with the community. Wallace and Bergeman (2002) used qualitative methods to examine the life stories and personal accounts of 10 older (aged 58-88) Blacks and found that spirituality was used as a resource during times of stress and hardships. Even now,



spirituality is well-documented and found to help Blacks cope, deal with health issues, raise children, develop relationships, and aging across the lifespan (Voisin, Corbin, & Jones, 2016).

Several researchers have examined the meaning of spirituality for Black communities. Mattis (2002) conducted a qualitative analysis of a sample of African American women ( $N = 23$ ) who were respondents of a more extensive quantitative study completed in a metropolitan area in the Northeast coast. Respondents described spirituality as helpful in navigating and accepting reality: confront personal limitations, connect and face existential questions on life lessons, develop purpose in life, maintain moral principles, and grow through life in health. Another study, a quantitative analysis of a representative sample of Blacks ( $N = 3,570$ ), Caribbean Blacks ( $N = 1,621$ ), and non-Hispanic Whites ( $N = 891$ ) with a total of ( $N = 6,082$ ), documented that 84% of the respondents found usefulness of spirituality and religion in their lives (Taylor & Chatters, 2010). Cohen, Thomas, and Williamson (2008) conducted a qualitative study that spanned across Jewish, African American Protestants and Caucasian Protestants ethnic groups, with the African American group defining spirituality as something that dwells within, having faith in God, and the ability to get through day-to-day struggles.

Numerous researchers have shown that spirituality has provided positive effects in the Black community, respective to mental and physical health (Brown, 2016; Holt, Clark, Debnam, & Roth, 2014; Koenig, 2012; Levin, Chatters, & Taylor, 2005; Musgrave, Allen, & Allen, 2002; Tuck, McCain, & Elswick, 2001). Additionally, researchers show that spirituality accounts for positive well-being in minorities,

specifically in Blacks (Holt et al., 2014; Ajibade, Hook, Utsey, Davis, & Tongeren, 2016). With chronic health issues in the Black community, spirituality is thoroughly documented to be an important variable in their lives (Becker, Gates, & Newsom, 2004; Bhattacharya, 2013; Harvey & Silverman, 2007; Holt et al., 2012; White, 2016). With spirituality indicated as a protective factor in the lives of minorities, specifically Blacks, it is important to explore this phenomenon as it pertains to aging, HIV, and stigma.

### **Spirituality, HIV, and Aging**

Numerous researchers have examined the impact of spirituality on the lives of people living with HIV about aging. In a review of 160 studies on people aging with HIV, spirituality, and religion is cited as a positive dynamic for aging with HIV (Zimmer et al., 2016). Researchers in a quantitative study examined stigma and psychological well-being among older gay/bisexual and straight men aged 50 and older ( $N = 640$ ) (Porter et al., 2017). With data yielded from the Research of Older Adults with HIV (ROAH), the researchers used a structural equation model to examine coping resources by sexual orientation. It was found that spirituality was an essential coping resource and a stronger buffer of HIV stigma and psychological well-being among gay/bisexual men with HIV. Vance et al. (2011) posited that aging with HIV presents many barriers to aging successfully. Aging individuals living with HIV may deal with several issues, such as various levels of stigma, decreased social support, and co-morbidities with HIV. Nonetheless, researchers suggest that older adults aged 50 and older living with HIV cope with the disease better by accessing spiritual and religious means (Vance et al., 2011). Barriers to successfully aging with HIV may be negotiated by older adults living with

HIV by accessing coping strategies acquired through spirituality (Brennan, Strauss, & Karpiak, 2010).

Having a diagnosis of HIV may facilitate growth and maturity. Vance et al. (2011) posited that adults aging with HIV report that their spirituality grew from being diagnosed with HIV. In a sample of 177 adults living with HIV, Kremer and Ironson (2014) found that 65% of the adults living with HIV specified that their spirituality grew after diagnosis with the disease. Similarly, in a qualitative secondary analysis of a larger study, Lutz, Kremer, and Ironson (2011) used a grounded theory approach to analyze characteristics of spiritual transformation of their sample ( $N=13$ ) and found that 100% of the sample indicated growth in their spiritual practices following diagnosis. In another secondary analysis, Brown (2016) accounted for examining sexual orientation and spirituality impact on psychological well-being among older Black men living with HIV/AIDS. Brown found that spirituality had a direct relationship with psychological well-being (e.g., personal growth, self-acceptance, purpose in life, environmental mastery, and autonomy). These findings may suggest that spirituality is important in producing increased coping skills in older Black men living with HIV/AIDS. Therefore, spirituality could potentially be a protective factor for this population.

Previous researchers have found that spirituality positively affects the lives of people living with HIV by improving coping ability, creating meaning to life and disease, feeling more connected, and providing an overall increased quality of life (Lorenz et al., 2005; Miller, 2005; Tarakeshwar et al., 2006; Foster et al., 2011; Dalmida et al., 2012; Brown et al., 2014; Buttram, 2015). However, other researchers suggest that spiritual

experiences of people aging and living with HIV are understudied (Hampton, Halkitis, Perez-Figueroa, & Kupprat, 2013; Pitt, 2010). Spirituality has positive effects on successful biopsychosocial functioning in aging, living with HIV, and other health challenges. Vance, Struzick, and Raper (2008) and Greer and Abel (2017) both identify the importance of spirituality on the health of aging individuals. Using a mixed method research design, Greer and Abel examined religious/spiritual coping behaviors of older African American women living with high blood pressure. Participants reported that the most common religious/spiritual coping behavior in navigating health issues is prayer and that God works through healthcare providers. The researchers point out that generalizability was an issue due to the location and the purposeful population of African American women. There are research implications in Greer and Abel's report that exploration of chronic health issues and spirituality of older Black men is warranted. Moreover, there is a need to explore this issue in older BMSM.

### **Spirituality and Older BMSM Living with HIV**

HIV is a chronic health issue that continues to gain attention due to the severity of the disease if left untreated. The literature on HIV and other chronic health issues show the advantages of spirituality on such diseases. Numerous researchers have explored the benefits of spirituality in various diseases such as diabetes (Sridhar, 2013), mental health disorders (Huguelet et al., 2016; Pesut, Clark, Maxwell, Michalak, 2011; Verghese, 2008), cancer (Holt et al., 2012; Visser, Garssen, & Vingerhoets, 2009), and hypertension (Kretchy, Owusu-Daaku, & Danquah, 2013). Advantages of spirituality have also been noted in cases of HIV (Doolittle, Justice, & Fiellin, 2016; Emlet et al., 2017; Himelhoch

& Njie-Carr, 2016; Lorenz et al., 2005; Miller, 2005; Porter et al., 2017; Szaflarski, 2013; Tarakeshwar et al., 2006). Although the research on spirituality and HIV is increasing, a limited number of studies have concentrated on older adults living with HIV and even less on older BMSM living with HIV (Brennan, 2008). There are only a few studies, which were previously cited, that explore spirituality related to older Black individuals in general. According to Galvan, Davis, Banks, and Bing (2008), this absence in the research literature is a possible result of stigma experiences, such as being a person of color, sexual minority status, and an older adult. Vance (2003) used field notes and interviews from a qualitative study of older adults living with HIV and found that self-selection bias, recruiting people with high levels of HIV stigma, and test savvy individuals were all potential barriers to engaging this population in research. He recommends adopting sophisticated recruitment approaches, rapport building, and addressing stigma as a potential deterrent. Access to older BMSM living with HIV may present an even greater challenge. However, a few studies have gained access to this population.

Karpiak et al. (2006) conducted a large-scale study of older adults living with HIV in New York City that explored various domains related to aging with HIV. Using a spirituality assessment scale to assess and measure various aspects of spirituality, the researchers found that spirituality was an essential component to lives of older people living with HIV, spirituality may be more important to Black than Whites and Latinos, and men may gain more from a sense of spirituality. In another study, Miller (2005a) qualitatively examined a narrative of an older gay Black man from a larger study he

conducted (Miller, 2005b) examining spiritual and religious strengths used to combat mechanisms of stigma, such as heterosexism and homophobia. The researcher found that spirituality was a resource that helped this participant cope with stigma experiences. Spirituality as a positive coping resource for this population is evident. However, there are no studies that examine the understanding of HIV-stigma experiences on spirituality use in older BMSM living with HIV. With the increased number of individuals 50 and older living with HIV, identifying as MSM and ethnic minorities, who experience HIV health disparities (Halkitis, Wolitski, & Millett, 2013) and benefits of spirituality, further examination and increased understanding of the experiences of spirituality in older BMSM age 50 and over.

### **Summary**

Research with older BMSM living with HIV is limited. Research is non-existent in the context of the understanding the effects of HIV stigma on spirituality use with older BMSM living with HIV in Washington, D.C. This study aimed to increase the understanding of the lived experiences of older BMSM living with HIV in the context of the effects of HIV stigma on their spirituality. Research studies on the experiences of older BMSM living with HIV are limited. There has been no research to explore the specific lived experiences of the effects of HIV stigma on spirituality use for older BMSM.

In this chapter, a brief overview of the MST and HIV stigma theoretical and conceptual frameworks are situated within the context of research with older BMSM living with HIV was provided. A review of the non-exhaustive literature of the

conceptualization of HIV stigma and spirituality is also provided. Although both concepts are difficult to define, a vast amount of literature describes and reports on essential domains that are potentially related to people living with HIV/AIDS. However, no literature was found that supports the exploration of the intended population of this study. In Chapter 3, an exploration of the methodology used for this study is explored. A qualitative approach using a transcendental phenomenology methodology for this study was applied.

## Chapter 3: Research Method

### **Introduction**

In this transcendental phenomenological study, I explored the lived experiences of BMSM 50 years of age and older living with HIV in the context of their experiences of the effects of HIV stigma on their use of spirituality. The following primary research question framed the approach to exploring the research focus: What are the lived experiences of older BMSM living with HIV in Washington, D.C. as it pertains to HIV-related stigma experiences on the use of spirituality? The two previous chapters provided details on the experiences of older BMSM in the literature surrounding HIV stigma and spirituality. The previous chapters also helped note what is known about the constructs. However, there is a lack of research as it relates to exploring these phenomena with older BMSM living with HIV. To address this gap, I conducted a qualitative study that drew on the understanding from older BMSM living with HIV personal experiences with the effects of HIV stigma on the use of spirituality. The current chapter includes an outline of the qualitative methodology this study used to explore the research problem.

Chapter 3 covers the research design and rationale, research questions, and the selected qualitative research tradition. A description of the role of researcher along with considerations for managing ethical issues, reflexivity, and potential biases are discussed. This chapter also includes a detailed discussion on the criteria for recruitment of study respondents, data collection, instrumentation, and the data analysis. Lastly, an account of the issues of trustworthiness is discussed.



### **Research Design and Rationale**

The following primary research question guided this study: What are the lived experiences of older BMSM living with HIV as it pertains to the effects of HIV-related stigma on the use of spirituality?

Additional subquestions included:

1. What are the lived experiences of older BMSM living with HIV?
2. How do older BMSM living with HIV describe their experiences of aging with HIV?
3. How do older BMSM living with HIV describe their experiences of HIV-related stigma?
4. How do older BMSM living with HIV describe the effects of HIV-related stigma on their use of spirituality?

Recent studies have been focused on the importance of conducting quantitative and qualitative research among older individuals living with HIV/AIDS within the last 5 years (Emlet, Fredriksen-Goldsen, Kim, & Hoy-Ellis, 2017; Emlet et al., 2017; Emlet, Shiu, Kim, & Fredriksen-Goldsen, 2017; Halkitis, 2013; Heckman & Halkitis, 2014). Moreover, other studies provided the topical concepts and phenomena for the present study (Emlet, 2007; Emlet et al., 2015; Haile et al., 2011). The central phenomena studied are the lived experiences of BMSM, 50 years of age and older living with HIV with experiences of HIV stigma on the use of spirituality are. HIV stigma and spirituality concepts are significantly studied in the social science literature (as discussed in Chapter 2). However, there is a lack of literature that explores the experiences of older BMSM

living with HIV stigma and spirituality. HIV stigma is a concept that is referred to as “a mark of disgrace” by some researchers (Mahajan et al., 2008, p. 3). Spirituality is a concept with multiple meanings, making it difficult to define. However, both concepts influence the lives of people living with chronic illnesses, specifically minority people living with HIV/AIDS (Earnshaw, Bogart, Dovidio, & Williams, 2013). This study aimed to capture the lived experiences of older BMSM living with HIV, precisely the effects of HIV stigma on the use of spirituality, through a phenomenological approach.

### **Research Tradition**

Qualitative research is primarily exploratory, used to uncover trends in thoughts and opinions while attempting to gain an understanding of underlying reasons and motivations of phenomena (Creswell, 2013; Ravitch & Carl, 2016). Qualitative research is found within a social constructionist interpretive paradigm that focuses on ways humans create the meaning of their social realities in specific language, social, and historical contexts (Thanh & Thanh, 2015). Philosophers and scholars like Immanuel Kant, Wilhelm Dilthey, and Max Weber, who are credited with crafting interpretivism, maintained that interpretivism helps avoid rigid structural processes such as positivism research strategies and uses a flexible and personal structure to research (Harrits, 2011) that is open to ascertaining meaningful human experiences (Black, 2006). Qualitative inquiry, phenomenology and phenomenological methods, and the role of the researcher are domains that align with the interpretivism paradigm.

Strategies under the interpretivism paradigm include a narrative approach, phenomenology, ethnography, case study, and grounded theory. Other methods of inquiry

were considered but rejected due to the inability to ascertain the essence of the participants' lived experiences. The narrative inquiry approach is almost identical to the phenomenological inquiry approach, but the focus is situated within a storytelling method in a chronological manner of ordering the meanings of experiences (Riessman, 2008).

The ethnography approach emphasizes the study of a culture as it is connected to ethnicity and geographic location (Reeves, 2008). This approach is used to focus on investigating a small number of cases, perhaps even one case in specific unstructured detail (Creswell, 2009). Researchers employ the case study approach to explore the understanding of specific occurrences, using individual, group, or institutions as a case (Creswell, 2009; Yin, 1984). The grounded theory strategy is used to generate or discover theory of experiences of participants (Glaser & Strauss, 1967).

This study aimed to gain a better understanding of the phenomenon of older BMSM living with HIV individual experiences with HIV stigma on the use of spirituality. I anticipated that the results would reveal themes that might help address challenges that older BMSM face with living with HIV, experiencing stigma, and using spirituality. The phenomenological approach in this study consisted of interviewing 10 older BMSM living with HIV who had experienced HIV stigma and used spirituality and lived in the metro Washington, D.C. area.

### **Transcendental Phenomenology**

Transcendental phenomenology was chosen to examine the experiences of older BMSM living with HIV as it relates to the effects of HIV stigma on the use of spirituality. Founded and grounded in work by Edmund Husserl, transcendental

phenomenology refers to the intentional examination of the human consciousness and the object of consciousness (Husserl, 1977). Applying transcendental phenomenological to qualitative studies result in a description of the perceived phenomena (Moustakas, 1994). Husserl pushed the transcendental agenda, and various scientists analyzed and added to his original efforts (Giorgi, 1970; Moustakas, 1994). Moustakas (1994) interpreted Husserl's constructs of transcendental phenomenology as a methodological framework for studying human experiences. One of the central methodological elements of transcendental phenomenology is the process of *epoche* (*bracketing*), or the setting aside of thoughts, judgments, and thoughts that lead to bias. Epoche is also known in other phenomenological approaches as bracketing in which researchers check their biases and preconceived beliefs about a certain phenomenon (Moustakas, 1994). Following epoche, the next important element of the transcendental phenomenological tradition is a transcendental phenomenological reduction. The transcendental phenomenological reduction process requires an account of each experience to provide meaning and existence of phenomena (Moustakas, 1994). Transcendental phenomenological reduction helps develop the textual descriptions (narratives) of the participants. Finally, the process of imaginative variation helps the researcher explore the accounts of the participants. This process involves synthesizing information gained from transcendental phenomenological reduction to create a representation of the experiences and meanings of the phenomena from the participant's perspectives. A phenomenological approach is suited for the study of lived experiences (Sheehan, 2014). Van Manen (2007) asserted that a phenomenology approach is used to gain an in-depth understanding of the features

of everyday experiences. TP is an appropriate philosophy for the qualitative paradigm in extracting the unique lived experiences of human conditions. TP allowed me to examine the lived experiences of the older BMSM living with HIV regarding the effects of HIV stigma the use of on spirituality in Washington, D.C.

### **Role of the Researcher**

My purpose in this study was of facilitator-observer as participants described their experiences. As a clinical social worker who has worked with this population through research, therapeutic practice and treatment adherence, I found that their essential voices were missing from the social work literature. To address this issue, I conducted this qualitative study and personal interviews with the participants to connect, enter a small section of their world, and illuminate their experiences of the effects of HIV stigma on the use of spirituality. Using phenomenological methods, I was to transfer the interview data that results in a comprehensive description of the phenomena. I participated in the process of bracketing to maintain bias by journaling and keeping field notes.

I have never experienced HIV or HIV stigma, and can only understand the experience of HIV stigma as described by the experiences of others who live with HIV, yet I have had my journey into what spirituality means and the utility of it in my life. I recognize my experiences with spirituality but bracketed personal expectations of the phenomenon to conduct this study.

The dynamic of the researcher and participant is important in qualitative research and can bring issues of ethical challenges, bias, and positionality in the research process (Ganga & Scott, 2006). I am a young, HIV negative, a gay Black male who could be

considered almost an insider due to my close cultural, linguistic, ethnic and national heritage (Ganga & Scott, 2006). Some researchers posit that this can be an issue in qualitative research with researchers being too close to participants (Ganga & Scott, 2006). However, other researchers provide that research within an individual's cultural community can be beneficial in access and awareness in both researcher and participants (Ravitch & Carl, 2016). Positionality and bias are critical to understand and control in qualitative studies due to the subjectivity and researcher being an instrumental part of the project. Bourke (2014) suggested that researchers address positionality and issues of potential biases with the participants in the study and understand and be clear about motivations with collecting data for the study with self and the participants.

### **Methodology**

Researchers recommend semistructured, in-depth individual interviews as the preferred method of data collection with the transcendental phenomenological method (Groenwald, 2004; Moustakas, 1994; Sousa, 2014). In-depth individual interviews allow the researcher to explore and experience the narratives of participants who have unique experiences with the phenomena (Creswell, 2009). For this study, I used individual semistructured interviews as the primary method of data collection.

### **Participant Selection**

The study included a purposive sampling design with a snowball sampling strategy. The population for this study was older BMSM living with HIV in the metro Washington, D.C. area. Individuals who identified as Black, MSM, and 50 years of age and older have shown to have the highest rates of HIV at 5,272.8 cases per 100,000

persons in D.C. (HAHSTA, 2016). Previous research with the older population living with HIV/AIDS suggests recognizing and accessing more “harder to reach groups” for studies surrounding aging and HIV (Emlet et al., 2017). The sample for this study was 10 older BMSM who were 50 years of age and older, living with a diagnosis of HIV, currently on an antiretroviral regimen and use a form of service for treatment of HIV in D.C. (e.g., treatment adherence, medical visits).

### **Sampling Strategy**

I used a purposive sampling with a snowball strategy for recruitment purposes. The requirement for this study was unique, and it was important to attain the identified population for this study. Purposive sampling allowed for the characteristics of the phenomenon to be explored by the intended population and produced rich-thick descriptions of the phenomena (Suri, 2011). The homogeneous sampling strategy was used because the research question addresses specific characteristics of the planned population of older BMSM living with HIV (Palinkas et al., 2015).

Twenty-five agencies in Washington, D.C. provide HIV/AIDS services. With the 25 potential sites, I chose from the list of agencies that had a focus on providing minority care, specifically to Blacks/African Americans. I reached out to the identified sites to introduce myself and the study. I received feedback from three agencies that work with Black individuals living with HIV/AIDS in D.C. However, only one agency out of the 25 AIDS services organizations in D.C. followed up with me and agreed to draft a letter of cooperation. I asked if an approved flyer could be placed in the community areas where potential participants could contact the researcher on their own volition. A request for a

letter of cooperation was also initiated to be able to hold interviews at the agency. Criteria for the study was advertised on the flyer with the following parameters: participants being active in treatment for the past 12 months, self-identify as Black, speak and read English, be absent of having any severe mental and/or cognitive challenges identify as having experiences with HIV stigma and spirituality, and older than 50 years of age. The participants were invited to correspond with the researcher directly through the flyer by calling an authorized Google voice number or through my e-mail. I received phone calls from a total of 16 potential research participants. At the time of contact, the potential participants were asked a series of questions to ascertain eligibility for the study (see Appendix F). Fourteen potential participants were found eligible for the study; the other two potential participants did not meet the criteria of living with HIV. Four out of the 14 eligible participants did not return my phone calls after two attempts to reach them. Only those who met the inclusion criteria were invited to participate in the interviews. The sample size for this study ceased at 10 interviews because data saturation was reached.

Data saturation includes the process of determining adequate, and quality data are collected to support the claims in a qualitative study that does not require new information or themes observed in a dataset (Guest, Bunce & Johnson, 2006; Mason, 2010). Because saturation can be an elastic concept, researchers should complete an extensive review of the themes within the aims of the study with an indiscriminate number of participants (Guest, Bunce & Johnson, 2006). Research shows that saturation is reached when there is a complexity of data reached that does not have the emergence of new information (Guest, Bunce & Johnson, 2006). Whereas TP is primarily concerned



with the individual lived experiences of the participants of the study, the focus was on quality and depth of the interviews for this study. According to Creswell (2013), the criterion for determining sufficient sample sizes is at data saturation. Gentles, Charles, Ploeg, and McKibbin (2015) conducted a meta-analysis of the three research traditions of grounded theory, phenomenology, and case study. The researchers found that sample sizes in phenomenological studies reviewed ranged between 10-30 participants. Similarly, Creswell recommended between 5-30 participants. Data collection and analysis happened simultaneously for this study. Data saturation was attained at 10 cases. At that time, no new information emerged, and several codes and themes began reoccurring.

### **Instrumentation**

Interviewing in phenomenological studies is the dominant method (Bevan, 2014). For phenomenological research, interviews should include questions that are descriptive/narrative, descriptive and structural, and clarifying (Bevan, 2014). Rubin and Rubin (2012) identified qualitative interviewing as an in-depth interview process that allows a researcher to enter the world of the participant (p. 2). To develop a list of interview questions, researchers should pay attention to the literature on the topic area and what needs to be answered. Similarly, Jacob and Ferguson (2012) posited that questions should be grounded in the research literature and lead to answering the unknown. However, Rubin and Rubin (2012) arguably reported that proponents of qualitative interviewing have discouraged the use of grounding interview questions in research literature because it might “blind the researcher” (p.135). So, very cautiously,

the investigator reviewed research questions, reviewed the literature, and developed the interview questions for this study. The interview protocol was the means used to seek the lived experiences of HIV stigma on the use of spirituality of older BMSM living with HIV. The interviews were slated for up to 90-minutes to complete in a private office at the agency site. The principal research question for this study was as follows: What are the lived experiences of older BMSM living with HIV in Washington, D.C. as it pertains to HIV-related stigma experiences on the use of spirituality? Further specific questions were used to inquire about the participants' experiences:

- 1: As an older BMSM living with HIV, tell me about what it meant to you when you were diagnosed.
- 2: Talk to me about your experience with aging and living with HIV
- 3: What are your experiences with HIV stigma?
- 4: Please describe your experience with HIV stigma as it relates to aging with HIV.
- 5: Tell me about the positive and negative aspects of your experience(s) with HIV stigma.
- 6: How do you define spirituality?
- 7: How do you use spirituality in your life with HIV? Use of spirituality and being over 50?
- 8: Please talk to me about your experiences of the effects of HIV stigma on your spirituality use.

9: What challenges (if any) have you encountered with HIV stigma on spirituality use?

10: What additional questions or information might you want to add to this interview?

The investigator used three instruments to collect data during the individual interviews.

The first instrument was the demographic questionnaire (Appendix A) that participants took about two minutes to complete at the beginning of the interview session.

Information on the questionnaire asked for information regarding the age, education level, occupation, employment status, length of years living with HIV, and marital and health status.

The second instrument was the interview guide (Appendix B). To maximize the content validity of the formation of the interview guide, the researcher used the HIV stigma conceptual framework relevant to the individual and cultural domains of the study, peer cognitive debriefing, and feedback (Brod, Tesler, & Christensen, 2009). The researcher developed the instrument to guide the interview process and to answer the research questions. The interview guide and demographic questionnaire were developed and tested among two peers as a field test using the Walden University standards for non-population pilot testing. The peers provided feedback on the interview guide regarding readability and connection to the conceptual frameworks of this study. The peers provided a level of cognitive debriefing of the semi-structured interview guide. The feedback from the researcher peers helped to refine, structure content, and make the questions representative of the concepts of the study.

The researcher used field notes after the interview process and data analysis stage for each interview (Appendix C). The field note instrument was drafted by the protocol described by Creswell (2013). It was designed to capture descriptive and reflective notes, dates, times, and place of the observations. Field notes allow researchers to gather additional data that could help with clarifying insights into phenomena and managing biases (Wolfinger, 2002).

### **Reflexivity Journaling**

Reflexivity is the process of systematically attending to the researchers' position and bias during a study (Patton, 2015). The reflexivity journal was a useful tool during the data collection, analysis, and interpretation of finding stages. I documented feelings and observations during the interviews, and any personal emotional reactions experienced during and after the interviews. I noted descriptive notes of the environment and with interactions with the participants. This process allowed me to monitor and manage any biases emerging throughout the study. During data analysis and transcription of the interviews, I added reflexive notes in the margins of the transcripts along with the codes to help deepen the analysis.

### **Procedures for Data Collection**

An underlying principle of transcendental phenomenology is that there is importance in exploring the lived experience of the human condition (Chan, Fung, & Chien, 2013). Therefore, interviewing is a key component of the process to extrapolate these experiences. Since this study was designed to explore the lived experiences, an

approach of semi-structured interviewing took place. Interviews were transcribed verbatim from the digital audio recorder.

Consistent with the transcendental phenomenology philosophy, in-depth individual semistructured interviews were conducted along with an offered meeting after analysis was completed to check the authenticity of the data. The researcher collected data through 30-90-minute in-depth interviews. The interviews focused on gathering demographic information, building rapport, signing the consent form, answering any questions that the participants had, and exploring the primary interview questions (See Appendix B for interview questions). The interviews were digitally audio-recorded with a recorder and transcribed verbatim. The digital files were stored on the desktop of the investigator with a triple password process. Field notes were taken to document interactions in the environment. The interviews were conducted at the selected agency. The researcher began establishing rapport with each participant during the initial phone call made to inquire about the research. The researcher received a letter of cooperation to post flyers and hold interviews at the site. A private office was provided to conduct the interviews. No participants denied interviews at the agency. So, there was no need to reserve an alternate space to conduct interviews. No participants had to reschedule during the study. Data saturation was reached at 10 participants.

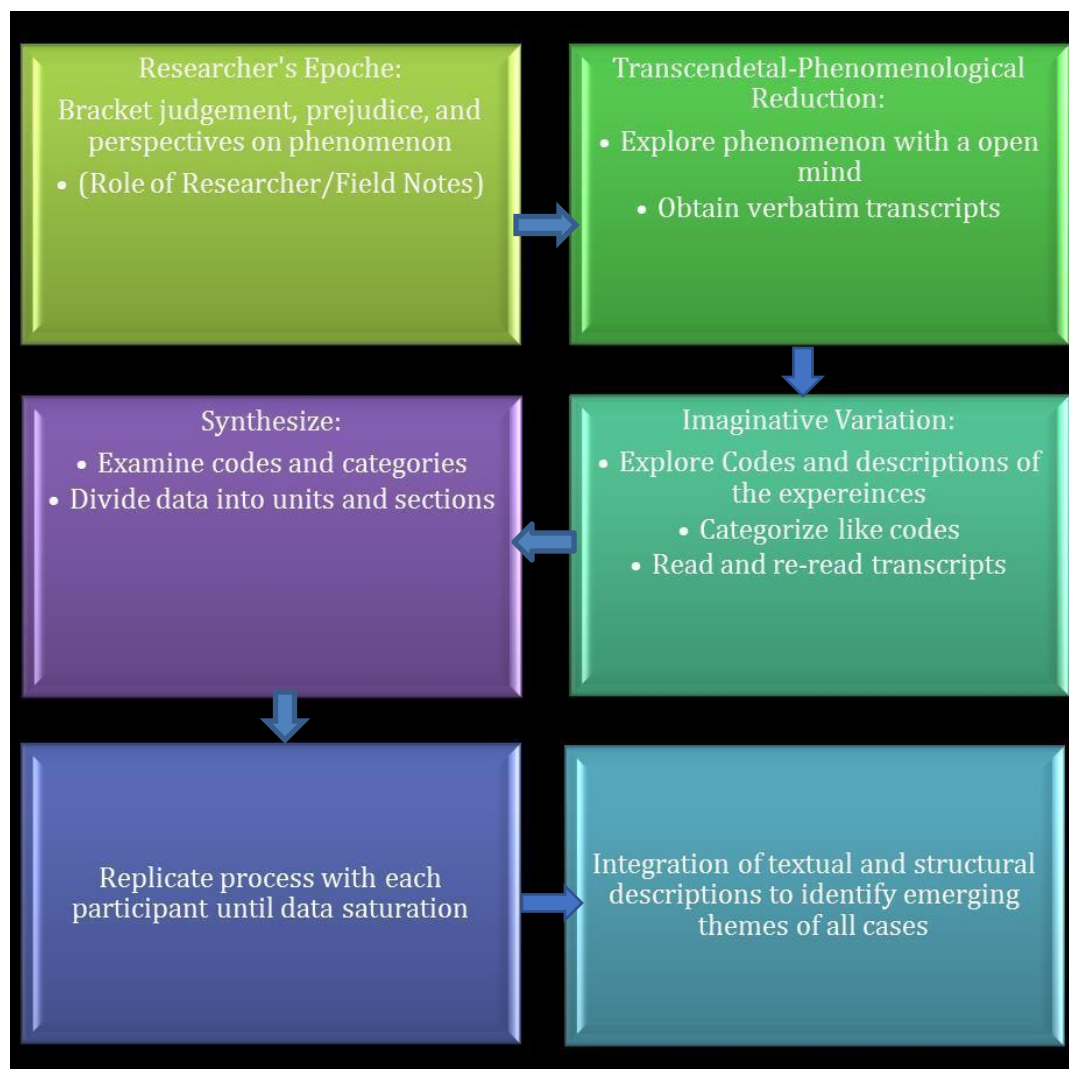
Participants of the study concluded the research process at the end of their interview. The participants were offered voluntary follow-up meetings face-to-face, telephone, and email to discuss the transcripts. The follow-up meetings were allotted up

to 60 minutes. All participants decided to conduct follow up meetings via phone, which lasted between 20-30 minutes.

### **Data Analysis**

As with most qualitative data, phenomenological data analysis involves the process of coding, categorizing and making meaningful interpretations of the phenomenon (Englander, 2012). Coding is the process of organizing and sorting data in qualitative research (Ravitch & Carl, 2016). Codes allow researchers to label, compile and organize raw data, which also allows for summarization and systemization (Saldana, 2016). This study used Moustakas (1994) modified van Kaam method analysis.

Moustakas presents an analysis model for phenomenological research that instructs researchers to 1) conduct verbatim transcription, 2) read and re-read transcripts, 3) divide data into units and sections, 4) integrate the sections with similarities, 5) revisit the raw data to help justify the interpretations, and finally 6) provide a critical analysis of your work in the research study (Kleiman, 2004; Moustakas, 1994). Moustakas (1994) adds that a common feature of the transcendental phenomenological data analysis is that the researcher describes their own experiences with the phenomena (epoche) (See Figure 2 for a depiction of data analysis).



*Figure 2.* Depiction of data analysis for phenomenological inquiry.

Data analysis focused entirely on the experiences of the research participants and the epoche (Bracketing) of the researchers' judgment. The data analysis and interpretation of results for this study included the researcher collecting data through 90-minute individual semi-structured interviews with open-ended questions; preparation of the data by transcribing the interviews (Horizontalization) and reviewing the transcribed interviews to find meaning, definitions, descriptions of experiences, and themes from the

data. An open coding system was used to explore the data for meaningful connections. Coding the data creates symbolic meaning to the information gathered during the study (Saldana, 2016). Coding also allowed the researcher to categorize the information across transcripts. After open coding, axial coding was used in reconstructing the connected data in a new way that lead to thematic analysis. The thematic analysis included a thorough line-by-line analysis of the transcripts and categories that emerged from the narratives that described the representation of experiences through themes (Saldana, 2016).

### **Trustworthiness**

Validity in qualitative research is often confusing due to the various terms such as trustworthiness, authenticity, validation, and credibility (Ravitch & Carl, 2016). Just as validity and reliability are important in quantitative research to ensure quality, the concept of trustworthiness is essential to ensure quality qualitative research projects (Ravitch & Carl, 2016). Trustworthiness is a concept that focuses on credibility, transferability, dependability, and conformability (Shenton, 2004; Ravitch & Carl, 2016). Trustworthiness in a research project refers to how the researchers can support that their findings are representative of the participant's true experiences.

### **Credibility**

The credibility of a study contributes to the belief that trustworthiness of data can be attained through strategies of triangulation and member checks (Shenton, 2004; Ravitch & Carl, 2016). Triangulation can happen in various ways in a research project. Strategies such as asking the same research questions of different study participants and collecting data from other sources such as documents can be used (Shenton, 2004;



Ravitch & Carl, 2016). In this study, I used a semi-structured interview protocol that was read verbatim to each participant. Additionally, member checks are helpful in establishing credibility in research studies. Member checks happen when the researcher requests that the participants review both the data collected and the researcher's interpretation of that interview data (Shenton, 2004). Member checks can be a lengthy process and can be difficult to complete. However, the process of filling in of gaps from previous interviews can be ascertained. For this study, I invited all 10 participants to participate in member checking. Each participant was sent a copy of their transcript via e-mail. I explored the transcript with each participant at an identified time over the phone to ascertain the accuracy of information from the interviews. There were no changes in the transcript data from the member checks. Having an accurate and detailed description of the topic researched was critical in promoting credibility for this study.

Additionally, practicing prolonged engagement in a research study builds trust and rapport with the participants to inspire rich responses (Patton, 2015). Rich-thick descriptions of the participants' experiences allow for an improved understanding of the phenomena. My engagement and attentiveness to the participants potentially encouraged rich and detailed responses (Patton, 2015).

### **Transferability**

Next, transferability in a qualitative study context is concerned with how studies can apply to broader concepts while maintaining true meaning of the data (Ravitch & Carl, 2016). It is important to note that transferability may not be feasible to a novice researcher due to the minimal efforts in having qualitative studies are generalizable

(Shenton, 2004). Although limited, transferability can be approached with the rich-thick description, which is described by Lincoln and Guba (1985) as a rich descriptive account of a phenomenon that leads to the evaluation of the phenomenon. From the evaluation, conclusions can potentially be transferred to other times, settings, situations, and people. This researcher conducted in-depth interviews with individuals who have had direct experience with the phenomena, which helps create rich-thick descriptions. Specific information in the rich-thick descriptions is emphasized such as the characteristics and experiences of the individual members. Stakeholders, research audiences, and participants can use this information to make comparisons across contexts (Ravitch & Carl, 2016).

### **Dependability**

Thirdly, dependability refers to the reliability of the data as constant over a period (Ravitch & Carl, 2016). Shenton (2004) posited that to address dependability in qualitative research, researchers must describe and be implicit in the research design for their study in detail. A future researcher should be able to replicate the work. Ravitch and Carl (2016) point out that there must be a sequencing of methods or as mentioned in Shenton (2004), overlapping methods, which describes a well-articulated rationale for the design. To ensure dependability, the investigator provided a detailed account of the methodology that could be replicated.

### **Confirmability**

Finally, per Ravitch and Carl (2016), “Confirmability, which is often described as the qualitative equivalent of the quantitative concept of objectivity, considers the idea

that qualitative researchers do not claim to be objective” (pp.189). Qualitative researchers do not set out to be objective but have findings that can be confirmed. Having information to researcher positionality and bias is crucial to creating confirmability (Shenton, 2004; Ravitch & Carl, 2016). To address the issue of confirmability, I separated all preconceived notions as a same gender loving Black male who share some minority statuses with the participants by bracketing my own experiences. I documented experiences in a reflective journal and the field notes during the data collection and analysis phase that helped mitigate bias.

### **Ethical Considerations**

Any research project that includes human participants requires approval from an Institutional Review Board that protects against exposure to harm. Before the research study began, an application to the Walden University’s Institutional Review Board (IRB) for research with human subjects was submitted and approved with approval number 01-03-18-0472131. The population for this study was vulnerable by definition. Therefore, it was important to have protections in place. No participants were approached before IRB approval. The participants of this study were adult males, age 50 and older, living with HIV, and who were free to volunteer and participate in this study. The participants could withdraw from the study at any time and for any reason after consenting to be in the study. There was no harm associated with participating in this study other than potential discomfort on elaborating on possible adverse life experiences. The participants were all provided with a list of local agencies that provide counseling services if they felt the need

to seek services. Participants of the study also signed an informed consent form that explained the procedures and the voluntary nature of the study.

### **Vulnerable Populations**

The researcher did have access to some vulnerable populations that are not intended of the study such as residents of a facility, mentally and emotionally disabled individuals, individuals who are in crisis, and economically disadvantaged individuals. To minimize safety and privacy risks for each group, participants received unique identifiers to maintain the confidentiality of data throughout the study. Participants were not pressured to participate. Participants initiated contact on their own or referred by the previous participant to establish interest in the study. The voluntary nature of the study was reiterated throughout the screening and consent process. Participants were able to withdraw from the study at any time for any reason. No participants withdrew from the study.

### **Anonymity and Confidentiality**

Each participant completed a consent form with a privacy clause. When the participant was identified as study eligible, they were asked to provide the researcher with a pseudonym or were provided with a unique identifier that followed them throughout the study to de-identify data and information. The participant's consent form required a printed unique identifier as a signature. Consent forms were scanned and placed on the researchers' home personal desktop computer under a triple password process. No personal identifiers were used. All files were labeled with unique identifiers. Transcripts, audio files, and files were stored through a triple lock password process on

the researcher's personal computer. Only the researcher has access to all the data and files. Once transcription and data analysis was completed, participants in the study had the opportunity to explore with the researcher the data gathered for continuity and verification of findings. All the participants participated in follow-up meetings via e-mail. However, no apparent information was used that could potentially link participants to the study.

### **Compensation**

Compensation and reimbursement for research participants is an active process for over 200 years in research (Pandya & Desai, 2013). Participants may have incurred charges (e.g., parking, transportation, time spent away from work) for participating in this study. I offered a \$30 Visa gift card as reimbursement to the participants. This reimbursement was provided to all participants, with the equal amount of the entire time of the study. It was discussed during the consent stage that the participant must have completed the entire interview to receive the reimbursement. The investigator personally funded the compensation.

### **Risks and Benefits**

There are minimal risks and benefits in this study. Recounting past and present experiences of living with HIV, HIV stigma, and spirituality could have caused some slight discomfort to the participants. However, the discomfort was no greater than everyday stress. To help mitigate any potential discomfort, the participants were offered counseling referrals from the respective agencies and a list of community resources that could further assist. The study yields potential benefits to society and indirect benefits to

the participants. Findings of the study add to the current literature to help society. Indirectly, participants benefit from sharing their experiences with another person, experiencing increased social contact, and gain personal satisfaction from contributing to a study (Meyer, 2013).

### **Summary**

A great need to understand the lived experiences of older BMSM living with HIV in the context of HIV stigma on the use of spirituality is warranted. This study sought to address the lack of literature available to the research community. This Chapter outlined the methodology by which the study was conducted. In this chapter, the steps in addressing the research questions, research tradition, and the role of the researcher were provided. The methodology, participant selection, data collection, and data analysis were also specified. Issues with trustworthiness are explored with ways to increase credibility, transferability, confirmability, and dependability of the study results. Chapter 4 focuses on the results of the data analysis. Chapter 5 concludes the study with a review of the findings, implication for social change and the social work profession, and recommendations for future studies.

## Chapter 4: Results

### Introduction

The purpose of this qualitative phenomenological study was to elucidate the lived experiences of BMSM living with HIV as it relates to HIV stigma and spirituality. The study involved the exploration of the impact of HIV stigma on the use of spirituality of older BMSM living with HIV. I employed a qualitative transcendental phenomenological research design to recruit 10 men using purposive sampling from the Washington, D.C. area. I adopted a modified van Kaam analysis using in-depth interviews. The study was guided by four research questions, with the following primary research question guiding the approach to exploring the research focus: What are the lived experiences of older BMSM living with HIV in Washington, D.C. as it pertains to HIV-related stigma experiences on the use of spirituality?

1. What are the lived experiences of older BMSM living with HIV?
2. How do older BMSM living with HIV describe their experiences of aging with HIV?
3. How do older BMSM living with HIV describe their experiences of HIV-related stigma?
4. How do older BMSM living with HIV describe the effects of HIV-related stigma on their use of spirituality?

In Chapter 4, I report the findings from the interviews of its 10 BMSM living with HIV. This chapter will include a description of the research site, demographics, sample selection, and the data collection and analysis procedures. The concepts of credibility,

transferability, dependability, and confirmability are also addressed. The chapter ends with a summary and introduction to Chapter 5.

### **Setting**

The interview site was the only site that responded to my contacts regarding recruiting for this study. The agency was selected due to the unique access and relationship it has with the participants of this study. The agency has a 25-year history of working with African American/Black men living with HIV in D.C. The identified agency is an AIDS service organization that was created by Black gay men living with HIV as a support group in the late 1980s. Over the past two decades, the agency has been focused on helping Black men living with HIV. Throughout the years, the agency began to provide mental health services, HIV counseling and testing, support groups, case management services, and treatment adherence programs.

Before IRB approval, I reached out to the manager of the HIV/AIDS service organization via e-mail and telephone to request a letter of agreement to display research flyers in group rooms and lobby areas for recruitment and space to conduct interviews. I requested the manager to place the recruitment flyers in various spaces for a 4-week period with an option to extend. I worked with the manager of the agency to develop a schedule to use a private space to conduct the interviews. The setting was an environment where people living with HIV/AIDS were likely to seek treatment adherence, psychological, and social services.

I instructed the manager and staff to direct potential participants to call the google voice number on the flyer if they had any questions. It was essential to the credibility of



the study that participants could self-select for the study without influence (Simon & Goes, 2012). As I received calls for potential participation, I screened and scheduled interviews at the site; the manager allowed me to use a space that allowed privacy. At the end of the 4th week of recruitment, 10 participants had been screened and interviewed. The recruitment flyers stayed up for an additional week. After the 5th week, recruitment ended due to data saturation with the 10 participants. I thanked the manager for allowing me to use the agency for the study purposes and removed the research flyers. Data collection took place from January 2018 to February 2018.

Once participants arrived at the site, I greeted them and escorted them to the private office space. The door to the office stayed closed the entire time for each interview. Interview times ranged from 30-60 minutes. Each participant was provided with a review of the consent form that required a signature with a pseudonym. The participants were reminded of the voluntary nature of the study and that they could end the study at any time for any reason without consequence. The participants were also reminded that their information would be kept confidential. The participants received a copy of the consent form at the end of the interviews. All interviews were digitally recorded and conducted individually. I provided the purpose of the study, outlined the procedures of the interview, and allowed any questions to be asked before beginning the interview process. I provided a \$30 VISA gift card as reimbursement of time, effort, and any charges incurred to meet at the research site. There were no issues presented by the participants at the time of the interviews that might have influenced the interpretation of the responses.

### Demographics

Table 1 illustrates the demographic profiles of the 10 participants of the study. Participants ranged in age from 50-68 ( $M = 60$ ). All participants identified as male and Black. Seven individuals identified as same gender loving and three as bisexual. The average years living with HIV were 30 years (range = 15-39). Almost all participants (70%) identified as single. Seven out of the 10 participants reported education over high school (70%). Four participants reported working full-time, one unemployed, three reported being retired, and two reported working part-time. Over half (60%) reported an undetectable status while 40% ( $N = 4$ ) reported active viral load statuses.

Table 1.

#### *Older BMSM Living with HIV*

Pseudonym	Age	Education	Employment	Orientation	Marital Status	Years with HIV	Stat
Oscar	54	Bachelors	Full-time	SGL	Single	33	UND
Mae West	63	High School	Part-time	BISEX	Single	31	UND
Smooth1	59	Some College	Retired	SGL	Single	39	UND
KatKid749	67	Bachelors	Retired	SGL	Single	32	AVL
Survivor55	54	Masters	Full-time	SGL	Single	30	AVL
Biscuit	62	High School	Full-time	SGL	Partnered	30	UND
Kevin	50	High School	Unemployed	SGL	Single	15	UND
HyDRO68	68	Masters Some College	Retired	BISEX	Married	25	AVL
Kain	53	College	Full-time	SGL	Single	30	UND
Rocky66	66	Ph.D.	Part-time	BISEX	Partnered	33	AVL

*Note.* ( $n = 10$ ). SGL = Same Gender Loving. BISEX = Bisexual. UND = Undetectable. AVL = Active Viral Load

### **Data Collection**

Data collection began when each of the 10 participants called to inquire about the study. During the initial call, the screening criteria (see Appendix F) was used to ensure that each participant met the specific criteria. Informed consent began once participants arrived at the field site and signed the consent form. Each participant was provided with a copy of the consent form. Field and reflective notes (see Appendix C) were taken during and after each interview to notate any reactions and environmental processes. I collected all data from face-to-face semistructured in-depth interviews and demographic questionnaires (see Appendix A & B). All interviews were conducted at the local HIV/AIDS service organization. I digitally recorded each of the 10 interviews, which ranged between 30 and 60 minutes. The demographic questionnaire took approximately 2-3 minutes to complete. The lengths of the interviews were determined by the amount of detail and description that each participant shared toward the interview questions. The interviews were semistructured with probing prompts to allow the researcher to delve into the experiences of the participants. All interviews were conducted in English. The interviews took place over a one-month period. All paper documents (i.e., consent form and demographic questionnaire) were scanned and placed in a triple password-protected folder on my desktop home computer. The digital recordings were coded with the respective pseudonyms and saved in the same protected location.

Each participant received a list of agencies in the D.C. metropolitan area that provides therapeutic services (see Appendix D). Follow-up meetings were also scheduled to provide member checking of the verbatim transcript to ensure accuracy. All 10

participants agreed to review the transcripts via e-mail and discuss via telephone rather than face-to-face meetings. Follow-up meetings ranged from 20 to 30 minutes.

After conducting each interview, I began transcribing the interviews immediately to stay close to the data but also to pay close attention to saturation. The transcription length of time ranged from 4 to 18 hours. Codes and categories started reoccurring with interviews five and six. As I transcribed and coded interview six, I continued data collection to ascertain full data saturation. Therefore, four more interviews were scheduled and completed. No new significant themes were emerging from the data, and I had reached data saturation at 10 cases. Additionally, I kept and maintained field notes for each interview that allowed for additional content for data analysis (see Patton, 2015). The interviews were transcribed, coded, and analyzed in Microsoft Word (MS Word). All the data collected are in electronic format and stored in a private password-protected folder on my personal desktop computer at home. I am the only person with access to this computer. There were no variations in the data collection process outlined in Chapter

### **Data Analysis**

The data analysis processed involved transcribing the interviews verbatim to immerse myself in the experiences of the participants. I developed a separate MS Word document to log data from the demographic questionnaires that were linked by the pseudonyms provided by the participants. The field notes were added to the coded transcripts to link data and information that lead to a richer analysis.

A modification of the van Kaam method of analysis of phenomenological data, as proposed by Moustakas (1994), guided the data analysis process. The van Kaam method consists of the following steps:

1. Researcher epoche: bracketing judgment, prejudice, and perspectives on the phenomenon.
2. Phenomenological reduction: exploring the phenomenon with an open mind and obtaining verbatim transcripts of information.
3. Imaginative variation: explore codes and descriptions of the participants' experiences. Categorize like codes and reading transcripts repetitiously.
4. Synthesizing: examining codes and categories by dividing data into units and sections.
5. Replicating process 1-4 with each participant to create textural descriptions based on the experiences linked to verbatim examples from each interview.
6. Development and identification of theme structures such as death sentence, concerns of loss of close individuals, disclosure issues due to stigma, and self-empowered spirituality, and described examples of these.
7. Adequately integrating textual and structural descriptions in a detailed account informed by the verbatim transcripts.

All sentence structures had equal value, so I began by reading and rereading the transcripts line-by-line for full immersion of the data. Each line was read and considered during the coding process. I also listened to the digital recordings during transcription and coding. I used a reflexivity journal to write down expressions and connections.

Reflexivity journaling allows a researcher to write about the research process of methodological use, logistics, values, bias, and more during conducting a study (Lincoln & Guba, 1985). Journaling during the process allowed for a consistent connection of the data and management of personal biases (Creswell, 2009).

Following the transcription stage, I created an MS Word document that began with anchor codes of the research questions to help guide and organize the coding structure throughout the transcripts. I began coding information from each transcript line-by-line. I used literal, descriptive, and process coding methods that are unique to beginning researchers learning to code, while using coding processes that are verbatim, descriptive, and action-oriented (Saldana, 2016). I used comment tracker in the documents to add codes and notes in the margins as I reviewed each transcript. After coding each transcript, I developed a list of initial codes related to each research question. In total, there were 400 initial codes throughout the 10 documents. Secondly, I tallied the number of codes across transcripts to categorize and group codes under the over-arching research question.

Thirdly, I examined the various codes to identify the relationships and patterns between them. I explored the emerging codes across datasets as part of the “imaginative variation” cycle of the van Kaam method process of data analysis that moves from categories to themes (Moustakas, 1994). To assist with mapping of the data, I used the frequencies of the code groups to create overarching themes that emerged from the participants’ experiences, and the researcher’s field notes. The 14 themes found were associated with each research question. For example, the themes of death sentence and

importance of family support emerged to answer the first research question. These are listed in Table 2.

Table 2

*List of Code Groups and Number of Coded Statements*

Groups or Themes	Anchor Codes	Number of coded statements
Death Sentence	Lived Experiences	25
Importance of family support	Aging with HIV	32
Complications with dating		17
Focus on holistic health		29
Increased loss of tribe		70
Isolation and Loneliness		33
Disclosure issues	HIV Stigma	40
Institutional vs. Internalized stigma		41
Mental health challenges		18
Self-medicating due to stigma		12
Stigma reinforces the use of spirituality		20
Definition of spirituality	Spirituality	19
Medication use dictated by spirituality		7
Empowerment through spirituality		10

*Note.* Anchor codes represent the research question



Lastly, after revisiting the original data sets, themes, digital recordings, contextualization of field and journal notes, I revisited the 14 groups of emerging codes to analyze connections between group codes further to describe themes with greater detail. For example, the group codes *increased loss of tribe* and *isolation and loneliness* were grouped to describe further experiences related to aging with HIV. Subthemes were used to help connect and relate the 14 code groups. Using subsumption, the process of placing information in a larger context (Brooks, McCluskey, Turley, & King, 2015) eight final themes emerged from the data analysis, (a) death sentence; (b) importance of family support; (c) focus on holistic health; (d) loss and loneliness; (e) “Institutional vs. internalized stigma: Internalized stigma wins every time”; (f) Stigma reinforces the use of spirituality; (g) definition of spirituality; and (h) empowerment through spirituality. Those themes are presented in Table 3.

In the original coding scheme, the themes of *complications with dating*, *disclosure issues*, *mental health challenges*, and *self-medicating due to stigma* were embedded into the theme of “*Institutional vs. internalized stigma, internalized stigma wins every time*” because the experiences shared compelled me to reconsider the dynamics of the participant personal accounts. After further analysis, the accounts related to the overarching experiences with HIV stigma were listed as subthemes. Additionally, the themes of *increased loss of tribe* and *isolation and loneliness* were renamed to *loss and loneliness*.

As coherence between themes were established, a narrative emerged that described the relationship of the themes to research questions, and conceptual and theoretical frameworks. The narrative is described in Chapter 5.

Table 3

*Themes and Subthemes*

Anchor Codes	Themes	Subthemes
Lived Experiences	a) Death sentence	
	b) Importance of family support	
Aging with HIV	c) Focus on holistic health	• “Not just my HIV”: Total health
	d) Loss and Loneliness	
HIV Stigma	e) “Institutional vs. Internalized stigma: Internalized stigma wins every time”	• Complications with dating • Disclosure issues • “I felt less than a penny with a hole in it”: Mental health • Self-medicating
Spirituality	f) Stigma reinforces the use of spirituality	
	g) Definition of spirituality	
	h) Empowerment through spirituality	• Medication use dictated by spirituality

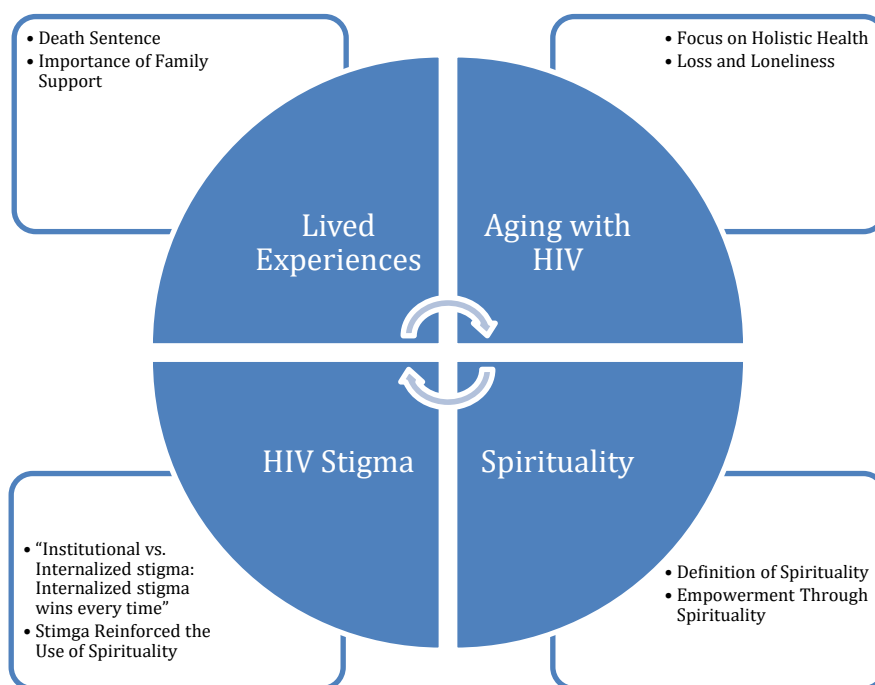
### **Evidence of Trustworthiness**

As outlined in Chapter 3, credibility, transferability, dependability, and confirmability are the criteria used to ensure trustworthiness of the data and results in qualitative research. To ensure credibility, I sought feedback of valid transcription of the interviews from the participants via member checking. All participants felt that there was an accurate portrayal of the phenomenon under investigation from the transcripts. All participants were sent the transcripts identified with the respective pseudonyms to ascertain credibility of their views. All participants provided their permission to go ahead with no edits of the transcripts. I also conducted data analysis simultaneous with data collection to identify themes and data saturation. Secondly, to ensure transferability and dependability, I described in detail the procedures for conducting this study that could be used in another setting. Finally, to ensure confirmability, I bracketed my personal bias of the phenomenon as a Black gay man using a reflexive journal. I used the reflexive journal throughout the data collection and analysis phases. With bracketing my personal experiences, the data presented is confirmed from the participants' experiences.

### **Results**

In this section, I present the study findings from the data collected from the 10 participants who are aged 50 and older, identify as BMSM, and living with HIV. The findings are illustrated through themes that emerged directly from the data. I have used the participants' words in quotations to provide further examples and supporting views of the themes. Participants provided pseudonyms that are used in conjunction with quotes to

describe their lived experiences further. The goal of this study was to gain an understanding of the lived experiences of older BMSM living with HIV as it pertains to HIV stigma on the use of spirituality. Eight themes with subthemes emerged from the data analysis (see Figure 3).



*Figure 3.* Anchor codes and the thematic cycle of lived experiences.

## Themes

All interviews were carefully and openly analyzed to answer each of the four research questions. During the interviews, I asked 10 open-ended questions with appropriate probing prompts to ensure clarity and understanding of the questions. I also provided each participant with a laminated sheet of questions to have for their reference during the research interview. The emergent themes from the interview questions were identified and connected back to the four research questions. The themes associated with

each research question are presented and defined, with participants' statements in the next four sections.

**Research question one.** The first research question was: What are the lived experiences of older BMSM living with HIV? Two themes emerged from the participants' responses about their lived experiences with HIV stigma and spirituality (Table 3). The experiences most commonly reported were death sentence and importance of family support. Participants' statements that support these themes are presented below.

***Death sentence.*** The most identified aspect of lived experiences of HIV stigma for most of the participants were thoughts of death and believing they would not live more than five years of being diagnosed. In addition, most participants identified that lack of knowledge, education, and stigma as contributors to the experience of having a death sentence. Katkid749 (67-year-old male diagnosed with HIV at 35 years of age) describes his experiences with the disease in the early 1980's as "It was devastating to see the death and decay around you, especially for Black folk. It was a death sentence. People were dying like flies. You would think 'Oh, God. Am I next?'" Mae West (63-year-old male diagnosed with HIV at 32 years of age) added,

I was diagnosed in August of 1986 and it was a death sentence. People did not live long with this thing and that was hard. They were dying like rabbits, overnight. You would see somebody today and tomorrow, and then you didn't recognize them next time. A week later, they would be gone. I was living yet waiting to die. It was devastating to me. You just wait to die because death was all around you and so present.

Biscut (62-year-old male diagnosed with HIV at 32 years of age) noted a relationship between thoughts of dying and how difficult it was to live with not having information about HIV as,

Being diagnosed in the early days when it really was a death sentence and dreadful, gives me perspective. You constantly think you are going to die, but you feel that you needed to live. How do you live with the stigma that was happening? There was no education or knowledge that helped us at the beginning. There was no way of having a 'good' life when you had this thing and thoughts of dying every day.

***Importance of family support.*** Importance of family support was a theme that showed high frequencies in the data. Although half of the participants noted beneficial relationships with their families, the other half noted difficulty and the importance of family support in mitigating factors such as self-medication to cope, internalized stigma, and negative impacts on the use of their spirituality. Kevin (50-year-old male diagnosed with HIV at 35 years of age) remarked that he found that family was important “most of the time” when he was first diagnosed. He stated,

“I would have to say that family is important most of the time when dealing with this thing. I was diagnosed at 35 and you would think that I would be okay or understand what to expect, but my family played a big role in me accepting this [pause] in accepting myself.”

Rocky66 (66-year-old-male diagnosed with HIV at 33 years of age) reported that family support was important all the time. He commented “It’s hard navigating life on your own.

It's even worst with living with HIV. So, family was a big thing for me in accepting this disease and being vulnerable to sit in settings like this to share."

Conversely, Hydro68 (68-year-old male diagnosed with HIV at 45) identified family to be a challenge with living with HIV. He said,

My family has not been helpful in dealing with this disease at all. I come from a very religious family that yells fire and brimstone at homosexuals or anything that goes against what God says. So, when I found out I was positive, I didn't tell anyone until I was 62 years old. My mom died not knowing and I was okay with this. It would have killed her quicker. I told my father and he stop speaking to me. I haven't talked to him to this day. But, it's something I must deal with. I have HIV and I cannot have the stress or stigma of my family put on me. The doctors say less stress, the better. I'm trying to be there.

Lastly, Smooth1 (59-year-old male diagnosed with HIV at the age of 20) remarked on personal accounts of family interactions. He stated,

When I was diagnosed I was disillusioned about the whole thing and went into a deep depression about it. My family tried to intervene, but they didn't understand the disease...being that they weren't educated about what HIV was, they thought it was communicable. They wouldn't let me use silverware or be around children. It was back when the stigma was heavy. Family was a weird thing and I could see how it would have been important, but they didn't have the right tools to be supportive.

**Research question two.** How do older BMSM living with HIV describe the experience of aging with HIV? Two themes and one subtheme emerged from the data regarding describing the lived experiences of aging with HIV (Table 3). The experiences most commonly reported focused on holistic health and loss and loneliness. Participants' statements that support these themes are presented below.

***Focus on holistic health.*** Most participants described their experiences with aging with HIV as not exclusive to just HIV. Many of the participants were more concerned about other morbidities that come with aging. Kain (53-year-old male diagnosed with HIV at the age of 23) described his lived experiences with aging with HIV as,

I think it is less about aging with HIV. Now, don't get me wrong, HIV has its issues on the body and aging has its issues on the body, but my HIV is well controlled with the medications I take. I am undetectable. That is the healthiest you can be in terms of HIV. Now, is my diabetes controlled? Am I at risk for cancer? These are the things I am more concerned with than just aging with HIV. And I just don't know if the current medical system can handle it. I'm tired of going to so many different people. My PCP [Primary Care Physician] should be able to treat a lot of this stuff.

Survivor55 (54-year-old male diagnosed with HIV at the age of 24) states "I'm surprised all the time to still be living this long, but that goes to show how medications have improved. Not just with HIV. Medications for everything is becoming more effective and making life easier for us." Katkid749 stated "...and the irony is that HIV is the least of



my concerns. I am having more trouble with diabetes and other things than with HIV.”

Oscar (54-year-old male diagnosed with HIV at the age of 21) explained his experiences in terms of “I don’t feel that aging with HIV go together for me. Aging is just aging. For instance, my HIV is okay, but I just had a knee replacement, and this is a priority to me now.”

***“Not just my HIV.” Total health.*** Biscut remarked,

The protocol is not the same as it was when HIV first hit the scene. We’re not worried about the medication per se but worried about the symptoms of medication on older victims and how diabetes, heart attacks, cancer, mental illness, neuropathy, all those things are correlated to aging with HIV. Cancer is very prominent now with those living with HIV, especially Black men...So, primary care doctors should be checking all of me, my infectious disease doctor should be checking all of me, not just my HIV.

Likewise, Rocky66 stated,

Medication use and the impact on the body used to be a main concern for me, but now I am more worried about high cholesterol and developing heart disease. I still worry about the HIV meds because they are toxic to the body, but it helps reduce my viral load. My total health is important as I age with HIV.

***Loss and loneliness.*** Every participant characterized part of their experiences with aging with HIV as dealing with loss and loneliness at some point throughout their lives. Mae West remarked, “...my concern now, as I age, at 63, becomes the loneliness

piece, where you want, you want to be with somebody, but HIV becomes a hindrance to be with someone.” Katkid749 added,

The hard part for me [aging with HIV] is that I have lost a lot of friends, but I also lost a brother, who I was very close to. And it was hard because suddenly now all these people who’d been a part of your life for all these years, they’re just gone, and like every week you hear there was...It just went on and on for years almost like every week, or every other week...and it was just dragging you down. It was very lonely.

Kain described his experience as “...tolerant of the idea of loss, death, and loneliness. As I get older, it becomes more difficult to date others, it becomes increasingly isolating, and your friends have all succumb to death via HIV or other means. It’s just life.” Biscut describes an experience that resonates with him and how he feels about the youth living with HIV. He stated,

I honor the younger generation with HIV, but they don’t know the side effects of going to *The Blade* (local LGBT newspaper), to look for a cocktail or place to go for the evening and looking to see if someone you knew had died. That’s what when we were 20, we had to look forward to every week. To see if somebody was gone. It was a very lonely process. That’s the age of whence I come. I don’t want the younger generation to experience that type of lost and despair daily.

Oscar described his experience with aging with HIV under lost and loneliness as,

I guess, you know, when you’re younger, it seems like you have a tribe of people that you kind of have, but as you get older, that tribe dwindles down...and you

don't make new connections because of the loss of your main tribe, and it becomes this big process of just feeling lonely. I just watched old members of my tribe go way, or die, or whatever...two of my closest friends have died in the last two years...and, that's just a part of aging.

**Research question three.** All participants responded to the question of: How do older BMSM living with HIV describe their experiences of HIV-related stigma? From their responses, one major theme and four subthemes emerged (see table 3).

*“Institutional vs. Internalized stigma: Internalized stigma wins every time.”* As a part of the interview protocol, I asked the participants to describe their experiences with HIV stigma. As I met with each participant, it became evident that each participant lived and experienced some form of stigma. Consistently, the participants described various experiences that included complications with dating and disclosure, mental health issues, and challenges with self-medicating as it pertained to living with HIV stigma. Mae West described his experiences as,

The stigma was...oh, it was hard. It was difficult to, to be honest about where you were, why you were doing the things you were doing. You know, why was I drugging? Why was I trying to kill myself? Because I got this this thing and I don't know how long this will be. The stigma from others were bad, but the stigma in my mind was worst. Institutional stigma vs internalized stigma...man, internalized stigma wins every time. The feelings of not wanting to be touched, like I was dirty...walking around like a time-bomb, getting ready to explode. Yeah, the stigma in your mind is worse than what anyone else can give to you.

***Complications with dating.*** Most of the participants remarked that due to internalized stigma, they had challenges with dating. Hydro68 shared “Before I was married, I had major issues with dating. The thoughts of disclosing, potentially sharing the virus, and just navigating those waters. It was hard.” Along with Hydro68, Kevin commented “I’m pretty sure I still have an issue with dating because of the stigma of HIV. I date but nothing past two dates. I probably need to go to therapy for that, but I haven’t yet.” Oscar shared “I had a difficult time for a while dealing with dating in general, regardless if the other person was positive or not. Just dealing with the feeling of feeling different made it hard.”

***Disclosure issues.*** The participants felt that issues with disclosing their statuses was related to internalized and institutional stigma. Smooth1 said,

I guess I had issues with disclosing because I didn’t share my status with people when we were having sex or something. I know it’s wrong, but I wasn’t. Maybe that was the stigma I had. Maybe that was the stigma that was in me the entire time, and just maybe that was what I was fighting.

Rocky66 added “The fear of having to talk to anyone about my status is stressful. Family, friends, colleagues, whoever, it is still stressful. So, I keep to myself and avoid. It is on a need to know basis.” Katkid749 stated,

I didn’t tell a soul because I had no idea what the reaction was going to be. And this was from people who I knew loved me, and cared for me, and were concerned about me. But this was a whole ‘nother kind of thing. It wasn’t like going to them and telling them I had cancer. It wasn’t like going to them and

telling them I had stole money from my boss. Those are the things that are forgivable. This disease, because of all connotations and because of the ugliness about it and the judgments... 'You're immoral. You're a whore. You're promiscuous. You're low down. You're nasty. You got this disease because you are nasty.' So, yea, it was easier just not to tell people.

***“I felt less than a penny with a hole in it.”: Mental health.*** Many of the participants explored and described experiences of stigma as it related to their mental health. Mae West stated,

I was losing my mind. I had lost it all. There was no sense of hope. I was less than a penny. I felt less than a penny with a hole in it. Ya know, they said that when a penny has a hole in it, it's useless. And that's how I felt. Hopelessness, depression, and despair just set in.

Smooth1 added, “Suicidal and homicidal ideations and attempts, depression, anger issues, unstable, and feeling like a dressed-up garbage can sometimes. That is how the stigma impacted just the mental part of my life living with HIV.” Kevin remarked,

I am pretty sure I didn't have a mood disorder before I was diagnosed. I mean...being same gender loving has its issues, but not like living with HIV. I was diagnosed with mood disorder eight years ago, and it has been a battle. The stigma from the community, from family, and self...man, it's just hard. I'm surprised most people living with HIV doesn't have mental health issues. Maybe they do, I don't know but it feels like I'm the only one sometimes.

Rocky66 reported,

Dealing with pressures of grad school, living with HIV and the self-stigma, and all other stigmas, I tried to harm myself by taking a bottle of sleeping pills. I was embarrassed and sought help quick. I was on antidepressants for a few years.

While most participants described these experiences, Biscut and Kain did not describe personal experiences of stigma related to mental health.

*Self-medicating.* Most of the participants believed that experiences of internal and external stigma attributed to times of self-medication. Smooth1 shared “I did the drugging and the drinking to stop the bad feelings of me living with HIV. To deal with the shame and guilt.” Comparably, Katkid749 stated,

I’d always been a big drinker because I was just a party girl, but my drinking started getting more and more out of control. And I started doing some really outrageous stuff. I remember this time with Jennifer Holiday, she was my home girl. Well, long story short is that I got sloppy drunk and got on stage and embarrassed myself. I say all this to show you how deep I went to cover up my insecurities, feelings of shame, and rejection due to my personal stigma.

Mae West added,

I shouldn’t be sitting here with you today. All of the drugs and alcohol that has been in my body [pause] I should not be here. I used to think to myself ‘You got this thing, so you should just drink and drug your way out. You going to die anyway.’ I’m not going to lie, I still think about using, but it’s not due to my HIV. Before, it was.

Kevin and Hydro68 did not describe experiences of self-medicating with drugs but identified self-medicating with food and overindulgence in sexual encounters.

*Stigma reinforces the use of spirituality.* Most of the participants shared experiences of how HIV Stigma reinforces their use of spirituality. When faced with internalized stigma, Survivor55 told of times where he would participate in spiritual practices such as prayer, meditation, and using his work as a mental health counselor to connect in difficult times with stigma. He said “When I’m feeling stigmatized, I go to my higher power, my spirituality. I do this through prayer, meditation, and the work I do as a counselor.” Biscut recalled a specific experience that reinforced his spirituality from institutional stigma. He shared,

...I was devastated, shamed, and felt guilty about living with HIV due to the way I was treated early on by places that was supposed to help like hospitals, doctor offices, etc. I remember when I found out, the doctor came into the hallway, no privacy, and just said that my friend and I was going to die in 6 months, so we should get our affairs in order. It was horrible. And if that wasn’t the worst...they had special days for people diagnosed with HIV and had to go to the back of the building to an area that wasn’t much bigger than this room through an unmarked door. I had to truly go inside and access a spiritual power to keep me going. The stigma was just horrible. There is no way I would have survived if I didn’t have it.

Katkid749 added,

For me, coping with HIV and the stigma is directly related to my identity as a spiritual person who understands the power of being a spiritual person and who

uses it very flagrantly in my life. It's what I share with people. I have this way of sharing myself with others through the things that they find beautiful in my home. If someone comes to my house and eyes a piece of art or specific item, I later gift it to them. I do that because it creates a space in my life to share positivity and love to them. It also helps me stay in a positive place with having a past of issues with stigma but living in a world full of strife, stigma, and other issues.

When challenged with stigma experiences, Rocky66 stated,

I immediately turn to my higher power to rectify feelings that breed contempt and misunderstanding. In 2018, it is no reason for stigma to be alive and well, but it is. So, when I feel it, I pray for the person or institution, and keep pressing my way.

**Research question four.** Research question four asked: How do older BMSM living with HIV describe the effects of HIV-related stigma on their use of spirituality? Two themes and one subtheme emerged (see table 3).

***Definition of spirituality.*** Most of the participants viewed spirituality as a personal choice with a personal power. Some even pushed the definition to a functional level that goes beyond personal choice of a higher power, but how personal activities define spirituality. A few even noted spirituality lacking a definition. Mae West defined spirituality as "...A connection with God or higher power. Something bigger than me, outside of me, but still in me that makes the inside work." Supporting, Kain defined spirituality as "It's a connection to a higher power that is outside of your internal world. It really is what you believe. It's not religion per se, but it can be found in religion." HyDRO68, who works in ministry, defined spirituality as "Something that is bigger than



ourselves that helps create a deeper connection to humanity.” Katkid749 definition agreed with HyDro68’s and took it a step further by defining it as “sense of self.” He explained,

Everything in my life that has seen me make it from one point to the next is based on my acceptance of myself as a spiritual person and having a connection to God. Am I religious? No. Religion is not something serves a purpose for me. My spirituality comes directly from God, understanding the things that I’ve learned. Spirituality is about how you identify, and how you imagine who you are, and how you accept your possibilities, and how you deal with the challenges of coping with troubled times. Having a sense of self. My coping with HIV and the stigma is directly related to my identity as a spiritual person.

Survivor55 spoke of a functional level of spirituality when coping with HIV. He stated “I use my spirituality with my clients, not talking about higher powers and stuff, but with the hope and the encouragement I hope to impart. It gives me hope and spiritual reassurance when I can do that.” Oscar noted that there was not a definition of spirituality for him, but he described spirituality on a functional level. He said, “I just try to be as conscientious of me being the best person I can be, which I fall short of doing every day, but being thankful and praying for others...sending out positive energy and attending church.”

***Empowerment through spirituality.*** Self-empowerment through using spirituality was a theme that was prevalent throughout the interviews of the participants. Many of the participants believed that using spirituality gave them feelings of trust and closeness to

their higher power to guide them on their journey living with HIV and coping with stigma. Rocky66 stated, “Using my spiritualism allowed me to feel empowered with innate abilities to take care of myself during the hard times.” Kevin agreed with Rocky66’s experience in that he believed that “When it comes to coping with HIV stigma, my spirituality empowers me to understand who I am, to stay positive, and focused.” Biscut described an experience that led to self-empowerment. He stated,

I went to [a major church in the area] with all these queens, who were supposed to be straight. Well, back in those days you didn’t say anything about it to anyone because of the stigma. One day the bishop decided to give an AIDS speech on Adam and Eve and not Adam and Steve. I was like, “Girl, you don’t want to go there.” He said “If there are any people in here that have issues who don’t want to hear, you can leave.” I was on the usher board and the choir. I slid myself out of the seat. Dropped the usher gloves on the ground and walked down the aisle and never went back. I stood up for myself and others who didn’t feel they could stand up.

Some of the participants also connected self-empowerment experiences through spirituality when faced with stigma and general issues. Smooth1 stated,

...the only thing I can say is that whatever stigma people have about my HIV is their business. My relationship with my God and spirituality helps me have that point of view. Even when faced with general life issues such as struggling with housing, my mental health, and other health issues, I turn to my spirituality to

keep me going. It empowers me to reconnect with myself to understand that I'm loved, and I am worthy.

***Medication use dictated by spirituality.*** Many of the participants explained that they let their grounding in spirituality dictate when to take what medications. Survivor55 shared,

When my doctor wanted me to take meds, I told her how I took meds over the past 30 years, which is to listen to the spiritual connection in my body. And if a certain medication didn't feel right with me, spirituality, I wouldn't take it. And AZT was one of those medications that I would not take. I had a lot of guilt by not taking it back then when it first came out. It was so many people getting sick and dying, and they were talking how toxic it was, but pressing us to take it. But, spiritually, something told me not to take it.

Mae West added,

I wasn't on medicine and some doctors would get mad at me and say, "We understand your spirituality, but we want you on meds" and I would say "No, not yet." I think spirituality and faith and believing and trusting in the spirit helped me make that decision.

Biscut described an experience that he felt led him to people in his life that helped him make the decision to begin medication treatment, which he attributes to his spirituality.

He said,

My doctor thought I was having some problems with my heart at one time and I went in and it turned to about a three-week stay in the hospital. I was set to be

released one day and they wanted to run a diabetes check on me which called for them checking my limbs and feet with a tiny pin. Well, that turned into a mess because my legs had swollen after that and I developed something called “Red man’s syndrome.” Well, anyway, this doctor came in and it was a host of medical students and residents in the room, she ordered them to leave. She said, “I know you have HIV and I know you aren’t taking medications, but your Black ass is going to start taking medications, aren’t you?” So, I started taking medications 5 years ago after living with HIV over 30 years. I believe my faith in God and spirituality brought that doctor to me. I will never forget, love her dearly.

Kevin shared,

I started taking medications when I was first diagnosed. Medications have improved from the first round of meds that were out before. But, I listened to that inside voice, maybe that was spirituality, but I heard that voice tell me to get on meds.

Kain added,

Medications were killing of people, specifically, black folks, so I did not take them, and I was severely sick at times. But, something spiritually told me to hold off until medications were helping and not harming. That’s what I did. My doctors kept pushing me to take meds because it was a huge push for treatment as prevention movement, but spiritually, I wasn’t ready to do so.

HyDRO68 reported how spirituality led him to stop taking medication that was “killing” him. He said,

I think that my spirituality saved me. I was on a combination of medications that were making me increasingly ill, and I was wasting away because of the heavy side effects. It was killing me. I prayed and prayed and sought spiritual guidance from elders in my community and I went off meds. It was scary but by that time they had came out with ATRIPLA, a pill to take once a day. I started taking it and my life got so much better. So, my spirituality really helped me in making that decision. It saved my life.

### **Summary**

The purpose of this study was to elucidate lived experiences of older BMSM living with HIV as it relates to HIV stigma and the use of spirituality. In this Chapter, I provided a review of the data collection and analysis process. I reported on findings from 10 participants that were selected using a purposive snowball sampling strategy through an AIDS service organization in Washington, D.C. Each participant completed an informed consent form with a pseudonym to maintain confidentiality and anonymity in the study. The responses from the interviews were used to explore the participants' experiences of HIV stigma and the use of spirituality.

The primary research goal was to explore the lived experiences of older BMSM living with HIV as it pertained to the effects of HIV stigma on the use of spirituality. Subsequent research questions included exploring experiences of aging with HIV, HIV stigma, and effects of HIV stigma on the use of spirituality. In response to research question one, most participants reported experiences with HIV as having a death sentence and the importance of family support. Findings associated with the second research

question revealed that participants felt that aging with HIV is focused on holistic health, and not just HIV. Participants also explained their experiences of loss and loneliness.

Answers to research question three revealed most participants believed that internalized stigma was greater than institutional stigma as it relates to dating, disclosure, mental health, and self-medicating. Participants also shared that Stigma reinforces their use of spirituality. Most participant's responses related to research question four provided their definitions of spirituality. Additionally, participants reported believing that they gained a level of self-empowerment through their spirituality as it pertains to HIV stigma and medication use.

The analysis identified eight major themes and six subthemes. The themes were (a) death sentence; (b) important of family support; (c) focus on holistic health; (d) lost and loneliness; (e) "Institutional vs. internalized stigma: Internalized stigma wins every time"; "I felt less than a penny with a hole in it": Mental health; self-medicating; (f) Stigma reinforces the use of spirituality; (g) definition of spirituality; and (h) empowerment through spirituality. The findings are useful for illuminating the experiences of HIV stigma on the use of spirituality for older BMSM living with HIV. In Chapter 5, an interpretation of the findings along with a discussion of the limitations, recommendations, social change implications, and implications for the field of social work is provided.

## Chapter 5: Discussion, Conclusions, and Recommendations

### Introduction

The purpose of this qualitative transcendental phenomenological study was to investigate the lived experiences of BMSM aged 50 and older living with HIV as it pertains to HIV stigma on the use of spirituality. The intention was to describe the lived experiences at the intersections of age, minority status of race and sexual identity, and gender. Older BMSM are living with HIV longer, which brings new age-related changes and challenges with living and coping with HIV. Individuals aged 50 and older make up almost 50% of the HIV population (CDC, 2015). With challenges and changes of maintaining a social support network, managing stigma and health comorbidities, mental health, and self-medicating, it is important to understand how older BMSM use spirituality as a coping resource. Research in earlier years of HIV and spirituality have not kept pace with the growth of the unique experiences of older BMSM living with HIV (Brennan, 2008; Doolittle et al., 2016; Haile et al., 2011; Hampton et al., 2013; Porter et al., 2017). The participants' descriptions of experiences allowed me to enter their worlds for a moment to collect information that led to answering the research questions. I could gather their experiences of aging with HIV, stigma, and the use of spirituality. The data ascertained from this study will equip stakeholders at the micro, mezzo, and macro levels in the development of policies and practices that inform interventions. Integrating HIV stigma-reducing information and the use of spirituality as it pertains to age, minority status of race and sexual identity, and gender will help the development process of policies and intervention practices.

Living with HIV, stigma, and using spirituality required the participants of this study to access levels of themselves that led to a transformative level of coping by moving from internalizing stigma to using stigma as a reason to use their spirituality. From the interviews and reflexivity journaling analysis, eight themes and six subthemes emerged. The themes were (a) death sentence; (b) importance of family support; (c) focus on holistic health; (d) loss and loneliness; (e) “institutional vs. internalized stigma: Internalized stigma wins every time”; “I felt less than a penny with a hole in it”; Mental health; self-medicating; (f) stigma reinforces the use of spirituality; (g) definition of spirituality; and (h) empowerment through spirituality.

In this chapter, I interpret the findings using the research questions, themes, theoretical and conceptual frameworks, and literature from Chapter 2 as guides. I move on to examining the limitations, provide recommendations for future research, and conclude with implications for social change and the social work profession.

### **Interpretation of Findings**

I present the research questions individually with relation to the findings from the data analysis. I also relate the findings to the literature and theoretical/conceptual frameworks. Although the main research question was centered on the lived experiences of HIV stigma on the use of spirituality at the intersection of age, minority race and sexual orientation status, and gender, participants’ responses covered experiences of their lives living with HIV. As a result, the interpretation of the findings will include all aspects of the participants’ experiences.



The chief research question of this study was: What are the lived experiences of older BMSM living with HIV as it pertains to the effects of HIV-related stigma on the use of spirituality? I address this question in the following narrative as it relates to each research question.

### **Research Question 1**

What are the lived experiences of older BMSM living with HIV? Two themes emerged from the participants' responses about their lived experiences with HIV stigma and spirituality.

**Death sentence.** Countless older men living with HIV are part of a cohort that did not expect to live long lives with the disease (Emlet et al., 2017; Halkitis, 2013). The participants identified that living with HIV felt like having a death sentence in the early stages of their living with the disease. Most of the participants identified that lack of knowledge, education, and stigma contributed to their experiences of feeling like having a death sentence, which aligns with the literature that examines MST on stressful experiences of people living with HIV (Dentato et al., 2013).

**Importance of family support.** The participants noted various positive and negative experiences about the importance of family support. Consistent with previous findings (Emlet et al., 2017; Vance et al., 2011), the presence and absence of family support crafted positive and negative experiences for the participants in this study. Kevin and Rocky66 emphasized the impact of family support in their lives at the beginning stages of living with HIV. Conversely, HyDRO68 and Smooth1 identified challenges with family members but understood the importance of family if equipped with education

on stigma and HIV. The importance of family support theme is supported by the literature around the enacted mechanism of stigma purported by Earnshaw and Chaudoir (2009).

## **Research Question 2**

How do older BMSM living with HIV describe their experiences of aging with HIV?

**Focus on holistic health.** In addition to navigating the experience of living with HIV from a medical perspective (e.g., medication adherence, labs, medical appointments), the participants' shared experiences of demanding medical providers to consider the holistic self and not just focus on their HIV. Similar to what was reported by Cahill and Valadez (2013), the participants reported on how the healthcare system may be ill-equipped to provide holistic care. Many of the participants shared experiences of how HIV is just one of the many issues they must deal with as they age. Mental health, medication, cancer, diabetes, and heart disease are just a few challenges the participants identified as areas of focus in addition to HIV.

**Loss and loneliness.** As older BMSM with an average of 30 years living with HIV, the participants recognized the increasing loss and feelings of loneliness in their personal lives and community. All participants characterized experiences of loss from describing early experiences with living with HIV, aging with HIV, and how there are significant feelings of loneliness for them personally and in their community spaces. These experiences of loss and loneliness have been noted in the literature that reviews instances of aging with HIV as it pertains to race and sexual minority status (Masten,

2015; Nevedal & Sankar, 2016). Also, the loss and loneliness characterized by the participants support experiences noted in literature that identifies loss of social networks for individuals living with HIV (Abbott & Williams, 2015; Cahill & Valadez, 2013).

### **Research Question 3**

How do older BMSM living with HIV describe their experiences of HIV-related stigma?

**Institutional vs. internalized stigma.** Stigma was an important issue identified by the participants. They shared experiences of multiple levels of stigma. All participants experienced institutional, community, internalized, and family stigma. As a result, the participants experienced complications with dating and disclosure, mental health, and self-medicating. Participants reported how self-stigma (internalized stigma) was a major factor with the most impact on various domains in their lives. Such stigma was often an important factor in navigating dating scenarios that lead to fearful experiences of disclosing and thoughts of infecting a partner. Second, stigma from the community was another major factor that led to issues with disclosing and mental health. Participants reported how the fear of being ostracized by the community due to stigma impacted sharing their status and their mental illness. Researchers have identified HIV stigma as a factor in the lives of people living with HIV (Blake et al., 2017; Grodensky et al., 2015; Haile et al., 2011; Porter et al., 2017). Blake et al. (2017) described a level of selective disclosure of the sample of 35 Black men living with HIV where most had disclosed to partners and family, but not the community. Interestingly, many of the participants in this

study spoke of experiences of not disclosing their statuses, or trouble disclosing due to stigma. Participants decided to disclose on a need-to-know basis.

Internalized stigma was often a chief influence, with institutional and community stigma following, on how participants treated themselves as it relates to mental health and the use of substances to cope with HIV and the stigma. Psychological well-being and stigma has been well researched within the aging population living with HIV (Brown, 2016; Emlet et al., 2017; Haile et al., 2011; Hampton et al., 2013; Van Sluytman, Spikes, Nandi, Van Tieu, Frye, Patterson, & Koblin, 2015). The participants' experience with stigma on their mental health corroborates the findings in the literature related to HIV stigma having a negative impact on well-being. Many of the participants revealed experiences of feeling hopelessness and despair, depression, mood issues, and suicidal and homicidal ideations. The literature on MST (Meyer, 2003) is aligned with this finding as it relates to internalized stigma and mental health outcomes. Often, the participants were forced to use substances to cope with HIV stigma.

Most of the participants had histories of using alcohol and other drugs. All participants used some form of substance in their experiences to help numb negative experiences to mitigate stigma. A few participants used food and increased sexual encounters to help manage the experiences of HIV stigma. Researchers have shown that substance use is highly correlated among people living with HIV and impact treatment adherence (Skalski et al., 2015). In this study, participants shared experiences of challenges with adhering to treatment and other coping resources during times of self-medicating.

**Stigma reinforces the use of spirituality.** Several participants reported moving closer to the use of spirituality in the time of need to cope with HIV stigma. This finding is one that stands out from the known literature. Recent and current literature supports the use of spirituality as a coping resource for older BMSM living with HIV (Brown, 2016; Doolittle et al., 2016; Haile et al., 2011; Himelhoch & Njie-Carr, 2016; Lutz et al., 2011; Szaflarski, 2013). However, no known literature or research supports this finding. When participants were faced with difficult and challenging times, they accessed their spirituality through practices of spirituality (e.g., prayer, meditation, giving back to loved ones, and utilization of their professional work). Historically, religion and spirituality have played a vital role in the lives of African Americans (Dalmida et al., 2012), and research on the utility of religion and spirituality for minorities of gender and sexual identities, specifically MSM are emerging (Vance et al., 2011). For the participants of this study, they found spirituality useful, and its use is supported by having stigma experiences.

#### **Research Question 4**

How do older BMSM living with HIV describe the effects of HIV-related stigma on their use of spirituality?

**Definition of spirituality.** Conceptualizing spirituality is an ongoing process for different groups and populations. The findings from this study added another level of conceptualization of spirituality for this group. The participants defined spirituality as a personal choice with a personal representation of a higher power and as a functional process. While part of the participants' definition of spirituality confirms what is

presented in Chapter 2, stressing the personal nature of spirituality and how it relates to self (Canda, 2013; Garg, 2017; Gomi et al., 2014; Pawar, 2016; Skalla & MaCoy, 2006; Starnino, 2016), the participants also highlighted the importance of the functionality of spirituality in their lives. The participants emphasized instances of using spirituality through their professional work to help connect with a personal higher power. For instance, Survivor55 shared that he felt that he was chosen by his higher power to become a counselor and work from a spiritual-led approach with people living with HIV. Participants also spoke of how spirituality increased a mindful presence practice of sending out positive energy to others and attending church services. Interestingly, most of the participants felt that their definition of spirituality helped develop a deeper connection with self. A deepened connection to self is seen in the journey of experiences with coping with stigma and finding a way to continue to feel connected to spirituality. This reinforces Emlet et al.'s (2017) finding of the importance of having a connection with spirituality and self. Most of the participants identified spirituality as separate from religion. As described in a study of 30 older adults living with HIV on the role of religion and spirituality on aging well, differentiating spirituality from religion was an important theme (Emlet et al., 2017).

**Empowerment through spirituality.** The participants reported how the use of spirituality led to feelings of trust and closeness to a higher power that guided them through their journeys. Feeling empowered by spirituality allowed the participants to advocate and be kind to themselves, handle challenging situations with psychosocial issues such as housing, mental health, and employment issues. In instances of strife,

especially with stigma, participants could empower themselves through their spiritualism. A longitudinal study in a sample of 177 HIV-positive individuals that found that spiritual empowerment was reported in 46% of the cases that allowed participants to cope with stressors (Ironson, Kremer, & Lucette, 2016) supports this finding.

An example of empowerment through spirituality noted was that many of the participants used spirituality to dictate their medication use. Antiretroviral medications are part of the equation of allowing individuals to live longer with HIV. In the formative years of the disease, medications had adverse side effects (De Cock, Jaffe, Curran, 2012). For many of the participants of this study, they felt that spirituality was leading them in making decisions to take or not take medication at the time of diagnosis and throughout the years living with the disease. Participants explained experiences of how spirituality helped shape the decisions to take medications, change medications that were harmful, and maintain treatment adherence.

### **Theoretical and Conceptual Framework Considerations**

The choice of the MST (Meyer, 2003) and the HIV stigma framework (Earnshaw & Chaudoir, 2009) was appropriate for this study. The frameworks helped illustrate that when older BMSM are pressured with HIV stigma experiences, stress reactions and stigma mechanisms are experienced (e.g., self-medicating, internalized and institutional stigma, and negative mental well-being). Stigma directed toward sexual minorities is a significant tenet of MST. When sexual minorities are introduced to stigma experiences, researchers have found that adverse health outcomes such as diminished quality of life, mental health issues, and physical health issues persist (Cramer, Burks, Ploderl, &

Durgampudi, 2017; Meyer, 2003). Participants of this study explored their experiences of stigma, prejudice, and discrimination and how those experiences impacted their lived experiences with HIV stigma. MST allowed me to explore the intersections of the participants racial, sexual, and health identities to help shape the discussion of the findings. Older BMSM living with HIV are placed in a disadvantaged social group as it pertains to gender, race/ethnicity, health status, and sexual orientation. Researchers have explained that members of disadvantaged social groups are exposed to more stress than advantaged groups (Dentato, 2013; Meyer, 2003). To gain a better understanding of the lived experiences of the participants as it pertained to HIV stigma, I used the tenets of MST to guide the focus of the current study. BMSM living with HIV have unique stress experiences that are chronic and socially based (Meyer, 2003). Therefore, using MST to explore the lived experiences of this population was imperative. HIV stigma is a stressor that was experienced by each of the participants in this study. The racial and sexual minority processes of prejudice and stigma of MST validates the stigma experienced by the participants in this study. The study provided further evidence to the use of MST in studying the lived experiences of older BMSM living with HIV. The findings from this study provided efficacy of the frameworks in the study of the lived experiences of older BMSM living with HIV. It affirmed the need to consider the intersection of minority identities of race and sexual identity, age, health status, and gender on how lived experiences are shaped by HIV stigma, and how coping resources such as spirituality is used.



This study also provided further support to the conceptualization of the HIV Stigma Framework (Earnshaw & Chaudoir, 2009) within the context of MST. In their conceptualization, the authors describe how stigma is experienced by people living with HIV through three mechanisms, enacted, anticipated, and internalized stigma (Earnshaw & Chaudoir, 2009). Within the stigma mechanisms framework, the findings of this study highlighted the impact of stigma experienced by the participants through their experiences of discrimination from others in the past and present that included family members, past lovers, co-workers, health providers, and friends. The participants' feelings of guilt and shame from thinking about future discrimination from others supported the second mechanism. All participants reported on the impact of endorsing negative attitudes and beliefs about self that leads to internalized stigma. The findings from this study further supported the conceptualization of how stigma impacts health disparities among older BMSM living with HIV. Chaudoir and Earnshaw (2013) posited that when an individual living with HIV experiences at least one mechanism of stigma, the process of how it impacts the individual (e.g., health behaviors, stress, biological changes) leads to physical and mental health disparities. This notion is evident in the findings of the current study. Most of the participants describe instances of challenges to physical and psychological health.

The present study affirms both the HIV stigma framework and minority stress theory as applicable to exploring the lived experiences of older BMSM living with HIV as it pertains to stigma and the use of spirituality. All mechanisms of stigma and minority stress are connected to the different patterns of stress towards sexual, racial, and health

minorities (Rendina, Gamarel, Pachankis, & Parsons, 2016). Each of the above models provided insight into the results of this study. Each man in this study found that they experienced various types and levels of stigma, but the most prominent being internalized stigma. These men shared stressful experiences that reinforced stigma mechanisms. However, they also spoke of how the stressful experience of stigma motivated them to use coping resources such as spirituality in their life with living with HIV.

### **Limitations of the Study**

Despite the collection and interpretation of the rich data, this study has several limitations. The focus of this research was to gain an increased understanding of HIV stigma and the use of spirituality among older BMSM living with HIV. The data gathered in this study is vital to the unique phenomenon of HIV stigma and spirituality phenomenon.

One limitation was the representative sample size and of the geographical location. I recruited from one AIDS service organization in the Washington, D.C. area for this study; thus, making generalizability to other BMSM living with HIV and aged 50 and older limited to the participants of this study. The findings do not apply to the general population of older BMSM living with HIV. The experiences of stigma, spirituality, and living with HIV may be different in other geographical regions or agencies. These findings describe the experiences of 10 older BMSM living with HIV in the Washington, D.C. metropolitan area. The identified agency that funneled the participants of this study is unique due to its social service history in the BMSM community. This agency has a specific mission to advance the agenda of reducing and managing HIV/AIDS in the

Black gay community. This agency was explicitly identified to access the participants of this study. Other agencies had opportunities to participate in the collaboration of this study. However, very few followed up regarding participation. Therefore, the findings of this study are limited to the experiences of the participants of this agency.

Another limitation of the study may have been the development of the interview questions. Conducting interviews require a level of skill to obtain in-depth responses (Patton, 2015). Three participants demonstrated moderate difficulty with following the open-ended question format. Therefore, I had to re-read questions and provide more probing information to retrieve typical responses. I used data from the literature and the HIV stigma framework to help structure the interview to help answer the research questions. However, I would have asked more questions about the specific types of stigma on the use of spirituality and if the use of spirituality impacted the experience of stigma. During the interview process through the interviews, I found myself wanting to know this information as I made notes and reflections in my reflexive journaling and reviewing the transcripts. With this being my first attempt at transcendental phenomenological analysis, I could have overlooked specific themes throughout the data. I did not conduct a pilot study for this study. Inter-rater reliability was not used to establish a complete measure of rigor. However, the transcendental phenomenological approach proved to fit the phenomenon under investigation.

During the interviews, I found that two of the participants showed difficulty with the open-ended nature. Consequently, perhaps a question and answer process occurred rather than a thoughtful, open response to lived experiences. However, probing questions

and analysis of the reflective journal were used to reduce the overall impact of this limitation.

Additionally, the issue of the sensitive nature of the topic of HIV stigma and HIV could have played a limitation concerning social desirability and honesty. Researchers have shown that the phenomenon of HIV stigma and HIV are topics that individuals living with HIV often find sensitive to explore (Blake et al., 2017; Carrasco, Arias, & Figueroa, 2017; Mahajan et al., 2008). The assumption is that the participants shared open and honestly with their responses to the interview questions and not due to desirability or untruths to appease the researcher. I acknowledged the sensitive nature of the topic at the beginning of each interview and encouraged participants to share openly and honestly.

Lastly, due to the unstructured nature of phenomenology, there is always a risk of introducing bias. The ability to bracket the researchers' bias is one way to help mitigate this limitation. The likelihood was always present of showing one participant more attention than another, or overstating the experiences of an articulate participant, or distorting the data by my own beliefs. For example, confirmation bias may have emerged during the process of this study. During the interview with KatKid749, I found myself having to maintain copious notes not to have my bias of wanting his information to align with what the previous three participants shared. During analysis, I had to challenge my assumptions of his codes against the codes of the previous participants. So, through the process of epoche, reflexive journaling, and member checks, I attempted to reduce the impact of my bias in presenting the participants' experiences.

### **Recommendations for Future Research**

The findings of this study established an increased understanding of HIV stigma in the lives of older BMSM living with HIV and on their use of spirituality. Current and recent research does not include a focus on the experiences of this population. Therefore, this study was needed to start the conversation and research process for accessing the unique lived experiences of older BMSM living with HIV. This study addressed a gap in the literature of the absence of the known experiences for this participant population (Haile et al., 2011; Kum, 2017). The participants described personal experiences of living with HIV, HIV stigma, and stigma on the use of spirituality. They described experiences of how stigma has impacted various life domains such as mental and holistic health, disclosure issues, complications with dating, self-medication, and the use of spirituality. However, there is a need for further qualitative review.

With the delimitation of the geographical location, it would be essential to engage in qualitative research that captures the experiences in various places to help shed light on the phenomenon on HIV stigma on the use of spirituality of older BMSM. The experiences described in this study represent ten individuals from an area that has a robust list of HIV services and a positive experience with HIV. It would be essential to gain a more in-depth understanding of experiences from other locations.

Another recommendation for future research would be to explore the avenues of how stigma reinforce the use of spirituality and medication use dictated by spirituality. These two findings were not anticipated. Previous researchers have suggested that HIV stigma may have negative impacts on the lives of people living with HIV (Porter et al.,

2017; Rueda et al., 2014; Slater et al., 2015). However, in this study, the participants added that their experiences with HIV stigma moved them closer to their spirituality through accessing ways to cope and feel empowered. Additionally, it allowed them to feel empowered and assured enough to choose when medication was appropriate for them to use, which from their perspectives, allowed them to live longer with HIV. It would be essential to explore a deeper understanding of these findings.

The current study was grounded in MST and contributes to understanding the participants' lived experiences. The participants of this study cited several experiences of stressful and challenging situations that impacted their experiences with HIV stigma and spirituality in a holistic way. The current study has implications for the continued use of MST in future research projects for older BMSM living with HIV regarding the minority status of race and sexual identity.

### **Social Work Education, Practice, and Policy Considerations**

Several implications for social work education, practice, and policy are offered to continue the dialogue about the HIV stigma on the use of spirituality of older BMSM living with HIV. First, I recommend that social workers work toward maintaining continuing education around HIV/AIDS and stigma with older BMSM. It is essential for social workers to maintain cultural competencies when working with this particular population. Understanding the unique experiences of the participants of this study could help curriculum development for social work educators to prepare social work student development with working with this population. With more training, education, and

seminars on stigma and HIV, there may be a reduction of stigma perpetuated by social work professionals.

Second, it is recommended that social workers use informed culturally appropriate instruments and assessments when practicing with older BMSM living with HIV that explores stigma and spiritual experiences with clients. Defining stigma and spirituality for the client will be significant in ascertaining unique past and present experiences that inform coping with the negative reactions of stigma. The proximal stress process of MST can be applied to social work practitioners developing cultural competent care practices (Meyer, 2003). Information gleaned from this study will allow social work practitioners to develop targeted practices that would attempt to address the issues of sexual orientation, internalized stigma/homophobia, and rejection sensitivity (Alessi, 2014) as it relates to race, age, and HIV status. Social work practitioners must increase their understanding of the relevant application of spirituality and stigma-reducing methods. Also, there is an important need for the emergence of an interprofessional relationship among members of faith communities to help develop culturally sensitive practices that target anti-stigma.

Finally, I recommend that policies be developed to help advocate for the need of stigma-reducing programs for older BMSM living with HIV. Information gleaned from this study should be used by social workers to support and lobby for legislature focuses on reducing stigma through innovative programs. Additionally, social workers need to advocate for older BMSM living with HIV to help reduce health disparities perpetuated by people living with and without HIV.

### **Implications for Social Change**

In this study, I have elucidated the experiences of older BMSM living with HIV as it pertains to their experiences of HIV stigma, HIV, and the use of spirituality. The findings of this study could be used to improve care strategies with this population by helping professionals incorporate the findings into direct practice strategies. The themes found hold essential information in promoting increased use of spirituality with older BMSM living with HIV and how they experience stigma. The implications for positive social change extend beyond understanding the unique experiences but suggest social change on individual, community, and society levels.

The current study highlighted the unique lived experiences of older BMSM living with HIV, which filled a gap in the literature. Having this nuanced information available, helping professionals can understand the challenges these men face. Professionals could address some of the problems by incorporating the information into their treatment practices, education material, and intervention development. Specifically, helping professionals develop best practices that are informed by the knowledge of this study. The data could potentially lead to culturally appropriate methods/techniques that may include (a) awareness of client's potential mistrust of professionals; (b) avoidance of over-and-under pathologizing; (c) normalization of the stigma experience; and (d) inclusiveness of personal spirituality inventory for a coping resource (Aleesi, 2014; Chazin & Klugman, 2014; Pachankis, 2007).

Challenges with HIV stigma is not new to the geographical location of the metropolitan Washington, D.C. area. However, there is often neglect of the community



due to the visibility of HIV and HIV stigma resources. More specifically, many of the current resources currently offered were birthed from the alarming rise of HIV in the D.C. population per capita (HAHSTA, 2016). The findings from this study suggest stigma continues to be an issue. Therefore, the community can gain an increased understanding of the information from this study to help shape community intervention programs that target reducing HIV stigma. AIDS service organizations could use the data from this study to design specific programs that target reducing HIV stigma for older BMSM by examining the themes and creating domains that provide particular focus. Community providers could also use the information to help advocate for policies that improve practice, policy, and research for HIV stigma and spirituality.

Social change in the lives of older BMSM living with HIV as it pertains to stigma must begin with the men experiencing HIV stigma and the social organizations that provide services to them. The U.S. Government has a National Strategy on HIV/AIDS that was posed in 2010 to address this domestic epidemic that describes ways to decrease HIV, manage HIV, and move towards a cure (Health Resources & Services Administration, 2017). One of the primary goals of the strategy is to reduce HIV-related health disparities and health equities by funding innovative models of service delivery that helps the improvement of care for minorities. The information gleaned from this study can help the governmental stakeholders develop and implement resources to programs aimed at targeting HIV stigma and spiritual focus among the older BMSM living with HIV. Stakeholders can facilitate this change through accessing the information in this dissertation to create and implement policies to address the gap in the

national strategy on HIV/AIDS on reducing health equity for minorities, specifically, older BMSM living with HIV.

### **Summary and Conclusion**

Although the U.S. is the leading country in advancing HIV treatment and prevention (HAHSTA, 2016), no studies have been conducted on HIV stigma on the use of spirituality. This study was developed to explore the gap of knowledge in the literature of the missing information of the unique lived experiences of older BMSM living with HIV as it pertains to HIV stigma and their use of spirituality. As such, the purpose of this study was to elucidate those experiences. This study used a transcendental phenomenological qualitative design with face to face interviews. Findings indicated eight themes and subthemes that explained the experiences of 10 BMSM living with HIV aged 50 and older about the phenomenon. The themes are: (a) death sentence, (b) important of family support, (c) focus on holistic health- “Not just my HIV”: Total health, (d) lost and loneliness, (e) “Institutional vs. internalized stigma: Internalized stigma wins every time,”- Complications with dating, disclosure, “I felt less than a penny with a hole in it”: Mental health, self-medicating, (f) Stigma reinforces the use of spirituality, (g) definition of spirituality; and (h) empowerment through spirituality-medication use dictated by spirituality.

Indeed, there is a need for more information on older BMSM living with HIV. Older BMSM have emerged as one of the most significant populations of the entire HIV population. In preparing for a population of individuals living longer lives with HIV, it is essential to have qualitative research that informs education, practice, and policy towards

older BMSM living with HIV. This population faces unique challenges such as ongoing issues with various forms of stigma, difficulties with aging, disclosure, health and mental health, race, loneliness, and isolation. The current dissertation has added to the discussion of HIV stigma and the use of spirituality. Lastly, this study will aid in the development of strategies that will contribute to improving health-promoting behaviors as it pertains to reducing HIV stigma and increasing the use of spirituality as a coping resource among older BMSM living with HIV.

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## Appendix A: Demographic Questionnaire

What is your age?	
What level of education have you attained?	<input type="checkbox"/> Less than High School <input type="checkbox"/> High School <input type="checkbox"/> Diploma / Trade <input type="checkbox"/> Bachelor <input type="checkbox"/> Masters <input type="checkbox"/> PhD <input type="checkbox"/> Other: _____
What is your employment status?	<input type="checkbox"/> Unemployed <input type="checkbox"/> Part-time <input type="checkbox"/> Full-time <input type="checkbox"/> Self-employed <input type="checkbox"/> Other: _____
What is your current occupation?	
What is your marital status?	<input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed
Number of years living with HIV?	
What is current health status?	<input type="checkbox"/> Undetectable <input type="checkbox"/> Active Viral Load <input type="checkbox"/> Unknown <input type="checkbox"/> Other: _____

## Appendix B: Interview Guide

Welcome and thank you for your participation. My name is Warren Miller and I am a doctoral student at Walden University conducting this interview as a part of a study to explore the lived experiences of older Black men who have sex with men with experiences with HIV stigma and spirituality use.

If at any time during the interview you wish to discontinue, please feel free to let me know. All of your responses are confidential. Your responses will remain confidential.

Your participation in this interview is completely voluntary. If at any time you need to stop, take a break, or leave, please do so. You may also withdraw your participation at any time without consequence

### Interview Questions

1. **As an older BMSM living with HIV**, tell me about what it meant to you when you were diagnosed.
2. Talk to me about your experience with aging and living with HIV.
3. What are your experiences with HIV stigma?
4. Please describe your experience with HIV stigma as it relates to aging with HIV.
5. Tell me about the positive and negative aspects of your experience(s) with HIV stigma.
6. How do you define spirituality?
7. How do you use spirituality in your life with HIV? Spirituality use and being over 50?
8. Please talk to me about your experiences of the effects of HIV stigma on your spirituality use.
9. What challenges (if any) have you encountered with HIV stigma on spirituality use?
10. What additional questions or information might you want to add to this interview?

I would like to take this time to thank you for your participation in this interview. No

identifying information will be used.

Appendix C: Field Notes Protocol

Descriptive Notes	Reflective Notes



## Appendix D: List of Agencies in D.C.

**24 Hour Access Helpline: 1-888-793-4357**

**Organization: Addiction Prevention and Recovery Administration (APRA)** Address: 70 N Street, NE, Washington, DC 20002 (NoMa-Gallaudet U – Red line) Phone: 202.727.8473 Website: <http://doh.dc.gov/apra> About: The Addiction Prevention and Recovery Administration (APRA) promotes access to substance abuse prevention, treatment and recovery support services. Prevention services include preventing the onset of alcohol, tobacco, and other drug use by children and youth, reducing the progression of risk and increasing protective factors that increase the likelihood of healthy, drug-free youth and their families. Treatment services include assessment and referrals for appropriate levels of care and maintenance of a comprehensive continuum of substance abuse treatment services including outpatient, intensive outpatient, residential, detoxification and stabilization, and medication assisted therapy. Recovery support services include wrap-around services, such as mentoring services, education skills building and job readiness training, to ensure a full continuum of care. APRA ensures the quality of these services through its regulation and certification authority as the Single State Authority for substance abuse treatment services. To receive services from the APRA, applicants must be DC residents. Proof of residency: DC Driver's License or DC Identification Card required.

**Organization: Alcoholics Anonymous Hotline** Address: 4530 Connecticut Ave NW, Suite 111, Washington, DC 20008 (Van Ness-UDC – Red line) Phone: 202.966.9115 Website: [www.AA-DC.org](http://www.AA-DC.org) About: Alcoholics Anonymous is a fellowship of men and women who share their experiences, strength, and hope with each other so that they may solve their common problems and help others to recover from alcoholism. Services through AA are free.

**Organization: AL-ANON Hotline** Phone: 202.635.2023 Website: [www.al-anon-alateen-dcmd.org](http://www.al-anon-alateen-dcmd.org) About: AL-ANON is a fellowship of relatives and friends of alcoholics who share their experiences, strength, and hope in order to solve their common problems. Services through AL-ANON are free.

**Organization: DC Department of Health – HIV/AIDS Administration** Address: 64 New York Avenue NE Suite 5001, Washington, DC 20002 (NoMa-Gallaudet U – Red line) Phone: 202.671.4400 Website: [www.dchealth.dc.gov](http://www.dchealth.dc.gov) About: The HIV/AIDS Administration partners with health and community-based organizations to provide HIV/AIDS prevention and care services to District and Washington area eligible residents. Services include medical support, HIV counseling and testing, data and information on HIV/AIDS programs and services as well as on the impact of HIV/AIDS on the community, education, information, referrals, and intervention services. HIV/AIDS SERVICES 5

**Organization: Howard University Hospital Comprehensive Area Resources, Entitlements and Services (HUH CARES)** Address: 2041 Georgia Ave NW, Washington DC 20060(Shaw/Howard University – Green/Yellow lines) Phone: 202.865.4564 Website: <http://www.howard.edu/huhcares/default.htm> About: The HUH CARES program provides comprehensive health services, including mental health counseling, to men, women, children and adolescents who are HIV positive. They serve clients who are uninsured or underinsured; clients must be DC resident

**Organization: Whitman-Walker Health** Addresses: 1701 14th St NW, Washington, DC 20009 (U Street – Green and Yellow lines) 2301 Martin Luther King Jr. Ave.SE, Washington, DC 20020 (Anacostia – Green line) Phone: 202.745.7000 Website: [www.whitman-walker.org](http://www.whitman-walker.org) About: Whitman-Walker Health offers free and confidential HIV testing and counseling to the general public. They use a rapid HIV test that delivers results in 20 minutes. Testing is available without an appointment. WWH also sponsors an HIV Mobile Testing Unit that goes into communities at risk and provides HIV testing and prevention Peer support program: 2 groups are available for individuals newly diagnosed with HIV. 1 group is for long term HIV survivors. 1 on 1 support services are also available. All group counseling services are free and ongoing. Applicants must register and go through intake process. For more information, call 202.797.3580 or email [peersupport@whitman-walker.org](mailto:peersupport@whitman-walker.org)

**Organization: Andromeda Transcultural Health** Address: 1400 Decatur Street, NW, Washington, DC 20011 Phone: 202.291.4707 Website: [www.andromedahealthcenter.org](http://www.andromedahealthcenter.org) About: The Programs currently being offered at Andromeda include: prevention and treatment of HIV/AIDS under grants from HAA HIV testing, primary care, case management, substance abuse counseling, mental health counseling, and referrals for housing and hospitalization; “Project Orion”, a city-wide medical mobile outreach vehicle that provides primary care services, case management, HIV testing, counseling and referrals; individual and group therapy for the dually diagnosed; a Children’s Program, with emphasis on depression and attention deficit disorder; a Latino women’s group every Thursday evening (free for all women, conducted in Spanish); an intensive psychosocial support group every Tuesday, Wednesday, Thursday, and Friday; adult psychiatric treatment with access to hospitalization at Washington Hospital Center and Howard University Hospital; and The Circulo de Andromeda provides alcohol and drug (non-opiate) prevention, outreach, and treatment. Program hours are Monday - Friday 9:00am to 5:00pm and Saturdays by appointment only. Most services are free for DC residents.

**Organization: Capitol Hill Center for Individual and Family Therapy** Address: 50 E Street SE, Washington, DC 20001 (Eastern Market – Blue and Orange lines) Phone: 202.543.4645 Website: [www.capitolhillcenterfortherapy.com](http://www.capitolhillcenterfortherapy.com) About: The Capitol Hill Center for Individual and Family Therapy provides psychotherapy services for children, adolescents and families. They accept some insurances and offer a sliding fee scale.

**Organization: Crawford Mental Health** Address: 2412 Minnesota Ave. SE, Suite 303, Washington, DC 20020 Phone: 202.688.3580 Website: [www.crawfordconsulting.org](http://www.crawfordconsulting.org)  
**MENTAL HEALTH 65** About: Crawford Mental Health offers clinical services including individual, family, group, and relationship/marriage counseling. They also provide psychological services, psychiatric services, individual and group substance abuse treatment, grief therapy, insight oriented therapy, play therapy, NTU psychotherapy, child and adolescent groups and adult groups. Forms of payment accepted include DC Medicaid, Medicare, Chartered Health/Beacon, Unison, PAC, Tricare, Cigna, Aetna, APS, United Behavioral Health, and HSCSN; a sliding scale is also offered for out-of-pocket payment.

**Organization: DC Department of Mental Health Access Helpline** Address: 64 New York Avenue, NE Washington, DC (NoMa-Gallaudet U – Red line) Phone: 1.888.793.4357 (1.888.7WE.HELP) Website: [www.dmh.dc.gov](http://www.dmh.dc.gov) About: This 24-hour, seven-day-a-week telephone line is staffed by mental health professionals who can refer a caller to immediate help or ongoing care. The Access Helpline can activate mobile crisis teams to respond to adults and children who are experiencing a psychiatric or emotional crisis and are unable or unwilling to travel to receive mental health services.

**Organization: DC Rape Crisis Center** Address: Locations in both NW and SE \*\* Call for locations Phone: 202.232.0789 24 Hour Hotline 202.333.7273 Website: [www.dcrcc.org](http://www.dcrcc.org) About: The DC Rape Crisis Center offers group and individual counseling services for rape and incest survivors and their families. In addition, the center offers child therapy, companion services and self - defense classes. Spanish-speaking staff on site. Services are free; must make an appointment – no walk-ins. Open Monday-Friday 9:00am-8:00pm.

**Organization: George Washington University – Center Clinic** Address: 2300 M Street NW Suite 910, Washington, DC 20037 (Foggy Bottom - Blue/Orange line) Phone: 202.887.0775 Website: [www.gwu.ued/~psyd/cc.html](http://www.gwu.ued/~psyd/cc.html) About: The Center Clinic at GWU provides individual and couples therapy, psychological testing, developmental assessments for infants, young children and adolescents, and ongoing family support as needed. Spanish-speaking staff on site. Fees are based on a sliding scale; the initial interview is free. Their hours are Monday-Friday 8:00am – 8:00pm and Saturday 9:00am – 2:00pm.

**Organization: Mary's Center** Address: 2333 Ontario Road NW, Washington, DC 20009 (Columbia Heights – Green and Yellow lines) Phone: 202.483.8196 Website: [www.maryscenter.org](http://www.maryscenter.org) About: Mary's Center serves low-income, immigrant families whose linguistic and cultural needs would otherwise go unmet by public or private health care systems. They offer advocacy services, Early Intervention programs, adolescent and family support, mental health counseling, entitlement benefits assistance, medical and health promotion programs, and family literacy programs. Program hours are Monday–

Friday 8:00am to 5:00pm and Saturday 9:00am to 5:00pm. The Adolescent Health Services Clinic is open two Saturdays per month from 9:00am to 4:00pm. Free walk-in HIV testing is offered Monday through Friday 9:00am to 5:00pm.

**Organization: Psychiatric Institute of Washington (PIW)** Address: 4228 Wisconsin Avenue NW, Washington, DC 20016 (Tenleytown – Red line) Phone: 202.885.5600 Website: [www.psychinstitute.com](http://www.psychinstitute.com) About: The Psychiatric Institute of Washington provides comprehensive behavioral healthcare for children, adolescents, adults and seniors suffering from mental health and addictive illnesses. They are a short-term, acute care hospital offering inpatient, partial and intensive outpatient hospitalization, as well as specialized treatment programs for chemical dependency. They accept most private insurances, as well as Medicare, Medicaid and self-payment.

**Organization: Wendt Center for Grief and Loss** Address: 4201 Connecticut Avenue, NW Suite 300, Washington, DC 20008 (Van Ness/UDC – Red line) Phone: 202.624.0010 Website: [www.wendtcntr.org](http://www.wendtcntr.org) About: The Wendt Center offers counseling for dealing with grief and loss issues, support groups, children's services, crime victim services, professional training and community education, crisis response and Recover: Support for Survivors of Sudden Traumatic Death. They also offer Camp ForgetMe-Not during the summer. Their hours are Monday-Friday 9:00am – 5:00pm.

**Organization: Damien Ministries The Administrative Offices and Food Bank of Damien Ministries** are located in the Woodridge neighborhood of Northeast Washington, DC. Support groups, advocacy and referrals to other related services are integral components of the Outreach Ministry. Contact: Rashid Darden: (202) 526-3020 x24 / [www.damienministries.org](http://www.damienministries.org) 2200 Rhode Island Avenue, NE, Washington, DC 20018

**Organization: Helping Individual Prostitutes Survive (HIPS)** Assistance to female, male, and transgendered individuals engaging in sex work in Washington, DC. Using a harm reduction model, HIPS' programs strive to address the impact that HIV/AIDS, sexually transmitted infections, discrimination, poverty, violence and drug use have on the lives of individuals engaging in sex work. Contact: (202) 232-8150 / [jeff@hips.org](mailto:jeff@hips.org) / PO Box 21394, Washington DC, 20009

**Organization: Us Helping Us, People into Living, Inc.** Address: 3636 Georgia Ave NW, Washington, DC 20010. Contact: Dianne Murphy. Telephone: 202-446-1100. UHU provides assistance to individuals who are looking to get tested for HIV/AIDS, mental health care, and treatment services to people living with HIV.

## Appendix E: Recruitment Flyer

## Older BMSM Living with HIV NEEDED!!!



I am studying the lived experiences of older BMSM living with HIV regarding HIV stigma and spirituality.

If you are an BMSM who...

- **is living with HIV;**
- **50 years of age or older;**
- **Willing to have interview audio-recorded;**
- **Identify as African American/Black;**
- **Receive current treatment;**
- **Has had experience with HIV stigma and spirituality;**

**Your experience would be most interest to me.**

Please contact me to arrange for a time when we can chat. Thank you in advance for taking the time to share your experiences.

**For more information and to enroll in this study, please contact the primary investigator:**

**Warren Miller**

***\*\*All phone calls/contact information will be held confidential.\*\****

***\*\* Reimbursement Incentive included\*\****

## Appendix F: Screening Questions

### Screening Questions:

1. Do you identify as Black/African American?
2. What is your age?
3. Have you had a sexual experience with another man?
4. Are you currently living with HIV?
5. Have you experienced any form of HIV stigma?
6. Have you experienced spirituality in your life?
7. Are you currently receiving treatment?
8. Are you willing to have the interview recorded?